

THE FUTURE CHALLENGES OF AUTISM: A SURVEY
OF THE ONGOING INITIATIVES IN THE
FEDERAL GOVERNMENT TO ADDRESS THE EPI-
DEMIC

HEARING
BEFORE THE
SUBCOMMITTEE ON HUMAN RIGHTS AND
WELLNESS
OF THE
COMMITTEE ON
GOVERNMENT REFORM
HOUSE OF REPRESENTATIVES
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THE FUTURE CHALLENGES OF AUTISM: A SURVEY OF THE ONGOING INITIATIVES IN THE FEDERAL GOVERNMENT TO ADDRESS THE EPIDEMIC

THURSDAY, NOVEMBER 20, 2003

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HUMAN RIGHTS AND WELLNESS,
COMMITTEE ON GOVERNMENT REFORM,
Washington, DC.

The subcommittee met, pursuant to notice, at 2:35 p.m., in room 2154, Rayburn House Office Building, Hon. Dan Burton (chairman of the subcommittee) presiding.

Present: Representative Burton.

Staff present: Mark Walker, chief of staff; Mindi Walker and Brian Fauls, professional staff members; Nick Mutton, press secretary; Danielle Perraut, clerk; Richard Butcher, minority counsel; and Jean Gosa, minority assistant clerk.

Mr. BURTON. Good afternoon. A quorum being present, the Subcommittee on Human Rights and Wellness will come to order.

And I ask unanimous consent that all Members' and witnesses' written and opening statements be included in the record. And without objection, so ordered.

I ask unanimous consent that all articles, exhibits and extraneous or tabular material be included in the record. Without objection, so ordered.

In the event that other Members attend the hearing, I ask unanimous consent that they be permitted to serve as members of the subcommittee for today's hearing. Without objection, so ordered.

The subcommittee is convening today to further examine increases in the occurrences of autism in the United States and to discuss the ways in which the Federal Government is providing services and financial assistance to autistic individuals and their families, and to learn more about their plans to deal with this growing epidemic in the future.

I was very pleased yesterday that we had the first autism conference. A lot of the information that Dr. Weldon and I and others gave to the conference I hope will be taken to heart by the scientists who are working on this issue. Hopefully we will be able to get some things accomplished that we have been working on for a long time.

And I think Secretary Thompson should be congratulated, as well as the President, for finally beginning to move on this.

About 15 years ago, autism was considered a rare disease, affecting about 1 in 10,000 children. Now, it is about 1 in 150 to 200. It is the third most common developmental disability that children face, even more prevalent than things such as Down's Syndrome and other childhood cancers.

According to a study released earlier this year by the California Department of Developmental Services, it was reported that the number of cases of autism in that State more than doubled since 1998 to December 2002. It went from about 10,000 to over 20,000. This explosive rate in the growth in autism is not merely being observed in California, but throughout the country.

Today it is reported that there is more than 1½ million individuals in this Nation that are afflicted with autism, and that the incident rates of these disorders continue to increase. They estimate that in the not too distant future we can see 4 million children affected. And the long-term ramifications of that from a cost standpoint is unbelievable, and our taxpayers will have to pay for that.

That is why I initiated an in-depth investigation into the autism epidemic over 4 years ago when I was chairman of the full committee. That initial investigation led to several committee hearings, bipartisan legislative proposals, and educational congressional briefings on autism for Members and their staffs.

In addition, various Federal agencies in the United States have also rightfully begun to acknowledge the present and future public health implications of the autism epidemic, and they are currently conducting and funding research into the causation and frequency of these disorders.

In an effort to better coordinate the efforts of the U.S. health agencies in response to autism, the Children's Health Act of 2000 established an Interagency Autism Coordinating Committee. The committee's primary mission is to facilitate the efficient and effective exchange of information on autism activities among the member agencies and to better coordinate their autism-related programs and initiatives.

Today, approximately \$10 billion a year is spent on these Federal projects relating to autism, including research, training for the teachers of the autistic individuals, and financial assistance to help families with the great financial burdens associated with caring for family members afflicted with an autism spectrum disorder.

If the upward trends of autism continue, the budgetary impact could increase 40 times to over \$400 billion per year by the year 2013, and that is something we can't let happen if it is at all possible.

Today the subcommittee has the privilege of hearing from the Honorable Peter van Dyck, the Associate Administrator from the Office of Health Resources and Services Administration at the U.S. Department of Health and Human Services, who is going to be testifying on the current programs and financial assistance that his office is providing to help families with autistic individuals.

I would also like to know, Mr. van Dyck, if you need more, how much more you need in order to do what has to be done, and we will see if we can't take your recommendations to the appropriations committee to get the money you need, because we want to make sure that we get to the bottom of this as quickly as possible.

In 2001, President Bush signed or pledged to leave no child behind, promising that every child in American should have the opportunity to receive a first-rate education. In an effort to fulfill his promise, the U.S. Department of Education is currently testing programs that would help to better train teachers who educate children with autism.

Ms. Ilene Schwartz, Director of the Training Center to Provide Evidence-based Educational Services to Students with Autism Spectrum Disorders, is here today to explain these exciting new educational initiatives.

In addition to these Federal initiatives in response to the autism epidemic, there are several nongovernmental and private institutions providing treatments that have been shown to improve the health and well being of autistic children.

Mr. Rick Rollens, co-founder of the MIND Institute at the University of California Davis, and Dr. Stephen Edelson, director of the Edelson Center for Environmental and Preventative Medicine, are going to testify before the subcommittee today to explain the therapies that their institutions have found to be of great usefulness in helping children with autism.

I firmly believe that if we do not take immediate steps to reverse the ever-increasing trend of growth in autism cases, we are going to be passing on a tremendous burden of responsibility in caring and providing for the autistic community to the future generations of America, and that is simply not acceptable.

It is my sincere hope that the Federal Government and independent researchers will find new and exciting ways to work together to once and for all find the root cause of the autism spectrum disorders, and to prevent this epidemic from harming more children.

There are two things that we really need to work on, and those who are here today I know are concerned as well about these issues. So I would like to mention those to you. We need to make sure that the program that is supposed to fund special education for children needs to be fully funded.

Right now we fund it at about 20 percent. We are supposed to be funding that at the Federal level of 40 percent. So I think we ought to contact all of our Representatives and Senators and tell them that needs to be increased, because the schools around this country, and I have experienced this with my grandson, the schools around this country are really strapped for cash as far as special ed teachers are concerned. And so we need to try to get more money into that fund so that the States, when they get the money, can filter it down to the local schools and communities, the moneys that are necessary to do that.

And like a lot of my colleagues, I forgot what my second is, but I will think of it during the meeting.

[The prepared statement of Hon. Dan Burton follows:]

Opening Statement of Chairman Dan Burton
Subcommittee on Human Rights & Wellness Hearing
“The Future Challenges of Autism: A Survey of the Ongoing
Initiatives in the Federal Government to Address the Epidemic.”
November 20, 2003

The Subcommittee is convening today to further examine increases in the occurrences of autism in the United States, and to discuss the ways in which the Federal government is providing services and financial assistance to autistic individuals and their families today, and to learn more about their plans to deal with this growing epidemic in the future.

Only 15 years ago, Autism was considered a relatively rare disease, affecting roughly 1 in 10,000 children. Since then, the growing rates of Autism are reaching epic proportions in this country.

Currently, conservative estimates of Autism rates in the United States indicate that 1 in every 500 children are afflicted with these various spectrum disorders, while scientific studies reported in the *Journal of the American Medical Association* have observed Autism rates of 1 in every 150 children, and the problem just continues to escalate. In fact, Autism has now become the third most common developmental disability – even more prevalent than Down’s syndrome and childhood cancers.

According to a study released earlier this year by the California Department of Developmental Services (DDS) it was reported that the number of cases of Autism in the

State increased from 10,377 cases in 1998 to 20,377 cases by December 2002. That means the caseload in California alone nearly doubled in a little more than 4 years!

This explosive growth in rates of autism has not merely been observed in California, but in States all across the country, and shows no sign of slowing down.

Today, it is reported that there are more than 1.5 million individuals in this Nation afflicted with Autism, and if the incidence rates of these disorders continue to increase, it is conceivable that the number of autistic children in America could reach 4 million in the next decade!

That is why I initiated an in-depth investigation into the Autism epidemic over four years ago during my tenure as Chairman of the Full Committee on Government Reform here in the U.S. House of Representatives. That initial investigation led to several Committee hearings, bi-partisan legislative proposals, and educational Congressional briefings on Autism for Members and staff.

In addition, various Federal agencies in the United States have also rightfully begun to acknowledge the present and future public health implications of the autism epidemic, and are currently conducting and funding research into the causation and frequency of these disorders.

In an effort to better coordinate the efforts of the United States health agencies in response to Autism, the 'Children's Health Act of 2000 (Public Law 106-310)' established an Interagency Autism Coordinating Committee (IACC). The Committee's primary mission is to facilitate the efficient and effective exchange of information on autism activities among the member agencies, and to better coordinate their autism-related programs and initiatives.

Today, approximately \$10 Billion a year is spent on these Federal projects related to Autism, including research, training for the teachers of Autistic individuals, and financial assistance to help families with the great financial burdens associated with caring for family members afflicted with an Autism Spectrum Disorder, and if the upward trends of Autism continue, budgetary impact could increase 40-fold to over \$400 Billion in Federal monies spent per year by 2013.

Today, the Subcommittee has the privilege of hearing from The Honorable Peter Van Dyck, Associate Administrator from the Office of Health Resources and Services Administration (HRSA) at the U.S. Department of Health and Human Services, who will be testifying on the current programs and financial assistance that his office is providing to help families with Autistic individuals.

In 2001, President Bush pledged to “leave no child behind”, promising that every child in America should have the opportunity to receive a first-rate education. In an effort to fulfill this promise, the U.S. Department of Education is currently testing programs that would help to better train teachers who educate children with Autism. Ms. Ilene Schwartz, Director of the Center for Training Personnel to Provide Evidence-based Educational Services to Students with Autism Spectrum Disorders, is here today to explain these exciting educational initiatives.

In addition to these Federal initiatives in response to the Autism epidemic, there are several non-governmental and private institutions providing treatments that have been shown to improve the health and well-being of autistic children. Mr. Rick Rollens, Co-Founder of the M.I.N.D. Institute at the University of California-Davis, and Dr. Stephen Edelson, Director of the Edelson Center for Environmental and Preventative Medicine,

will testify before the Subcommittee today to explain the therapies that their institutions have found to be of great usefulness in treating children with Autism.

I firmly believe that if we do not take immediate steps to reverse the ever-increasing trend of growth in autism cases, we will be passing on a tremendous burden of responsibility in caring and providing for the autistic community to future generations of Americans. That is simply not acceptable.

It is my sincere hope that the Federal government and independent researchers will find new and exciting ways to work together to once and for all find the root cause of Autism Spectrum Disorders, and to prevent this epidemic from harming more of our children.

I look forward to hearing from our witnesses today. They deserve our thanks and full support as they lead the daily battle against this terrible affliction.

Mr. BURTON. With that, Mr. van Dyck, would you rise so we can swear you in and we will get started? This is a common practice. [Witness sworn.]

Mr. BURTON. You are recognized, Mr. van Dyck.

STATEMENT OF DR. PETER VAN DYCK, ASSOCIATE ADMINISTRATOR, OFFICE OF MATERNAL AND CHILD HEALTH BUREAU, HEALTH RESOURCES AND SERVICES ADMINISTRATION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. VAN DYCK. Thank you, Mr. Chairman. Good afternoon, Mr. Chairman. I am Dr. Peter van Dyck, HRSA's Director of Maternal and Child Health Bureau. Dr. Duke sends her regrets that she was unable to appear today due to a prior commitment that she made before receiving your invitation. Thank you for the opportunity to talk about our programs for persons with autism spectrum disorders.

The Maternal and Child Health Bureau is one of five bureaus within HRSA, and it is charged with promoting and improving the health of our Nation's mothers and children. Our mission today is to provide national leadership, and to work in partnership with States, communities, public-private partners, and families to strengthen the maternal and child health infrastructure, to build knowledge and human resources in order to assure continued improvement in the health, safety and well being of mothers and children, and this population includes children with special health care needs, which would include children with autism, pregnant women, infants, children, adolescents and women of reproductive age. We also serve fathers as appropriate.

Title V of the Social Security Act authorizes appropriations to provide and to promote family centered, community-based coordinated care for children with special health care needs, and to facilitate the development of community-based systems of services for such children and their families.

By statute, in the Maternal and Child Health Services Block Grant under Title V, 30 percent of the Federal dollars are designated to support programs for children with special health care needs, including those with autism. All States meet this requirement, and most far exceed the required 30 percent requirement.

Children with special health care needs include all children who have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions, and who also require health and related services of a type or amount beyond that required by children generally. This also includes children with autism.

Estimates are that about 18 million children in the United States have these special health needs. HRSA is responsible for developing and implementing a plan to achieve appropriate community-based service systems for these children with special needs, including those with autism and their families.

This program is developed around six components. In 2003, the budget for those six components was approximately \$22 million, and I will describe very briefly each of those six components.

The first, we administer a grant program that supports a national network of communities dedicated to developing and improving service integration for young children with special needs. The

program also works with the Federal Interagency Coordinating Council to identify barriers to coordinated service delivery for these children and to disseminate successful strategies for integrated services.

One mechanism for dissemination is a demonstration grant program, and we currently have four States receiving grants. We have a national resource center which addressed these multiple issues related to interagency collaboration, community recognition, and interprofessional practice.

The second area is partnerships in all aspects of decisionmaking. We promote family centered care through collaboration between families and health professionals and policymakers to improve the quality of life for these special needs children.

Current grant funding includes support for four family to-family health information centers, and two national resource centers on family professional partnerships. The third area is supporting comprehensive health care through the medical home concept. This program was developed in partnership with the American Academy of Pediatrics, and that is to improve access to appropriate services of routine health care and the integration of medical services within the community of services required by these children.

It is a collaborative effort among child health professionals, children with special health care needs, their families, to assure universal access to medical homes as well as support systems for the providers who serve these children.

Currently we have grants in 15 States for medical homes. We have a national resource center, and we have funded these to the tune of about \$3.6 million. Now, in 19—in 2004, rather, an additional \$1.5 million was planned, of which 300,000 will support a resource center on service delivery issues specific to autism, and that will be coming out in 2004 as a competitive grant.

No. 4, we support access to adequate sources of insurance and financing for needed services. Increasingly, children with special health care needs, including those with autism, are receiving their care in managed care plans. The unique health problems of these children challenge managed care organizations to provide the full continuum of medical health and social services within their cost and utilization constraints.

We seek to address these issues, including the identification of these children, quality assurance systems, provider networks, and financing strategies. Currently we fund six States in grants to improve financing in this kind of a situation with managed care, two national resource centers, and they also provide technical assistance to address these unique issues.

No. 5, we seek to provide early and continuous screening identification and early intervention. Infants and children with these high risk conditions must be identified early in order to help assure that they and their families receive care and assistance to prevent future morbidity and to promote optimum development.

Advances in brain research, the Human Genome Project, and increased effectiveness of early intervention have expanded our capacity to identify children with special needs and to offer early intervention. We have current funding of \$10 million, which includes grants to almost all States to receive or to achieve universal

newborn hearing screening, and assure linkage to a medical home early intervention and family to-family support.

And, six, we look to assure successful transitions of children to all aspects of adulthood. Health care services must not only be delivered in a family centered manner, but they must prepare individuals to take charge of their own health care and lead a productive life.

We currently have grants in five States and a national resource center and provide technical assistance to address these special issues.

All State Title V programs funded by us at the Federal level receive funding from HRSA and the Maternal and Child Health Bureau to address these six components. Now, we also have a few other areas where we are providing specific assistance.

HRSA serves on the Interagency Autism Coordinating Committee, which you mentioned earlier, which meets on a semiannual basis to enhance coordination and effectiveness of autism research and service activities across the Federal Government.

As part of the national training curriculum on medical homes, the National Center for Medical Home Initiatives has recently completed a specific module to provide early developmental and behavioral screening, and this center receives nearly a million dollars annually to support universal implementation of the medical home concept for children with special health care needs.

Last year we awarded a million dollar grant to Geisinger Health System in Danville, PA, and this is to develop a medical home model of care and related set of tools that will be used to improve early detection, access to diagnostic and evaluation services, and continuity and appropriateness for care for individuals, specifically with autism and their families.

Educational tools from this grant will be disseminated to State programs and communities to strengthen and expand integrated community services of care for children with autism. We recently, recently being October of this year, hosted an expert work group meeting for families of children with autism, and the primary goal of this workshop was to provide us with information on service needs from the family's perspective and to discuss with families potential strategies to address the identified needs.

This information will be shared at the next meeting of the Interagency Coordinating Committee, and we have two long-standing programs that are relevant to the training of health professionals to serve persons with autism and other developmental disabilities. The Leadership Education and Neurodevelopmental Disabilities Program [LEND], funds 35 programs in universities across the United States to train individuals from a wide variety of professional disciplines to assume leadership roles and to ensure high levels of clinical competence to improve the health of children who have developmental, neurodevelopmental or other related disabilities such as autism and mental retardation.

The interdisciplinary faculty and trainees include audiologists, dentists, health administrators, nurses, nutritionists, OTs, PTs, physicians, psychologists, social workers, special education professionals and speech and language pathologists. These programs are currently funded at \$18 million a year, and we also fund nine per-

haps in universities of higher education to enhance the behavioral, psychosocial and developmental aspects of general pediatric care, and these programs support fellows in behavioral pediatrics to help in their development for leadership roles as teachers, researchers and clinicians. And clearly this will aid in the identification and treatment of children with autism.

We also funded a study addressing autism entitled "The Early Detection of Autism: Comparison of Three Screening Instruments," where we are comparing the efficacy of three different screening instruments to identify children as early as possible, children and infants as early as possible, for signs of autism.

And we have the health centers, community health centers program. Once a child as a primary care patient presents suspected symptoms of autism, primary care clinicians seek a specific referral, generally outside the purview of the health center, but within the community that health center serves.

The primary care clinician may tap any available resource, such as a community mental health center or other federally funded program, such as the Children With Special Health Care Needs Program which I mentioned earlier.

Well, this provides a brief summary of HRSA's activities to provide assistance to persons with autism. We call upon our partners, all of us together, to have a common effort to develop and improve community-based systems of care for children with special health care needs and their families.

It will take joint efforts of all partners to make a difference for these children and these families.

Thank you very much for the opportunity to appear before the committee.

[The prepared statement of Dr. van Dyck follows:]



**Statement for the Record
Subcommittee on Wellness and Human Rights
House Committee on Government Reform
United States House of Representatives**

Health Resources and Services Administration

Activities to Support Persons with Autism Spectrum Disorders

Statement of

Peter C. van Dyck, M.D., M.P.H.

Associate Administrator of the Maternal and Child Health Bureau

Health Resources and Services Administration

U.S. Department of Health and Human Services

November 20, 2003

I am Dr. Peter C. van Dyck, the Health Resources and Services Administration's (HRSA) Associate Administrator for the Maternal and Child Health Bureau (MCHB). Thank you for the opportunity to testify today about the HRSA programs to assist persons with Autism Spectrum Disorders (ASD).

Since 1912, HRSA programs have provided a foundation and structure for assuring the health of mothers and children. The Maternal and Child Health Bureau (MCHB), one of five Bureaus within HRSA, is charged with promoting and improving the health of our Nation's mothers and children. The legislative authority for our programs is found in title V of the Social Security Act, section 501.

Our mission today is to provide national leadership and to work in partnership with States, communities, public-private partners, and families to strengthen the maternal and child health infrastructure, ensure the availability and use of medical homes, and build knowledge and human resources in order to assure continued improvement in the health, safety, and well-being of mothers and their children. This population includes children with special health care needs, including children with autism, pregnant women, infants, children, adolescents, women of reproductive age and fathers. Section 501 (1) (D) of title V authorizes appropriations "to provide and to promote family-centered, community-based, coordinated care for children with special health care needs and to facilitate the development of community-based systems of services for such children and their families".

By statute, 30% of the Maternal and Child Health Services Block Grant under title V is designated to support programs for children with special health care needs, including children with ASD. All States meet, and most far exceed this requirement. Indiana, for

example, receives a total federal allocation that exceeds \$12 million through the Block Grant and the percentage Indiana earmarks for children with special health care needs (CSHCN) is 33.2%, an amount exceeding \$4 million. Nation-wide, the total federal allocation to the States through the title V Block Grant is approximately \$600 million. The percentage that States earmark for CSHCN is 34.8%, or in excess of \$200 million.

With regard to children with special health care needs, HRSA plays a leadership role in the development and implementation of comprehensive, community-based, family-centered, coordinated systems of care. Children with special health care needs are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and also require health and related services of a type or amount beyond that required by children generally. This includes children with autism. It is estimated that 18 million children in the United States have these special health needs.

HRSA is responsible for developing and implementing a plan to achieve appropriate community-based service systems for children and youth with special health care needs, including those with autism, and their families. This plan is organized around six components. The total fiscal year 2003 budget for this initiative is approximately \$22 million. HRSA provides funding for these six components as follows:

1. Develop inclusive community-based systems of services. HRSA administers a grant program that supports a national network of communities dedicated to developing and improving service integration for young children with special needs. The program also works with the Federal Interagency Coordinating Council (FICC), funded and coordinated by the Department of Education, to identify barriers to coordinated service delivery for CSHCN, including children

with ASD, and to disseminate successful strategies for integrated services. One mechanism for dissemination is a demonstration grant program. Current discretionary grant funding includes grants to States for statewide implementation, a national resource center, and contracts to address multiple issues related to interagency collaboration, community recognition and inter-professional practice. \$1.9 million was funded in 2003.

2. Develop partnerships in all aspects of decision-making. Work in this area has two purposes: (1) to promote family-centered care through collaboration between families with CSHCN and health professionals and policy makers to improve the quality of life for CSHCN, including children with ASD, and their families as well as that of the health care delivery system; and (2) to promote the integration of culturally competent values, practices and policies into existing service systems to address issues related to quality, access, and disparities. Activities are initiated through integrated services leadership, national cooperative agreements, grants, and a variety of local, State, and national partnerships. Current discretionary grant funding includes grants to support family-to-family health information centers, two national resource centers on family/professional partnerships and cultural competence, and issues related to family-centered care for children with special health care needs and their families. \$1.8 million was funded in 2003.
3. Ensure access to comprehensive health care through the Medical Home Program. This program was developed in partnership with the American Academy of Pediatrics (AAP), to improve access to appropriate sources of routine health care and the integration of medical services with the community services required by

CSHCN. It is a collaborative effort among child health professionals, CSHCN, including children with ASD, and their families to assure universal access to medical homes, as well as support systems for the providers who serve these children. Partnerships with families have been established for the planning, development, and oversight of the medical home. Current discretionary grant funding includes grants to States for statewide implementation, a national resource center, and contracts to address multiple issues related to impact, cost and quality. \$3.6 million was funded in 2003; an additional \$1.5 million is planned for 2004 of which \$300,000 will support a resource center on service delivery issues specific to autism.

4. Ensure access to adequate sources of insurance and financing for needed services.

Increasingly, CSHCN, including children with ASD, are receiving their care in managed care plans. The unique health problems of these children challenge managed care organizations to provide the full continuum of medical, health, and social services within cost and utilization constraints. This program seeks to address these issues, including the identification of children with special health care needs, quality assurance systems, provider networks, and financing strategies. Current funding totals \$3 million in grants to States for implementation and two national resource centers, one located at the University of Florida and the other located at U.C.L.A., to develop identification and financing strategies with health plans and technical assistance to address unique issues.

5. Provide early and continuous screening, identification and early intervention.

Infants and children with high risk health conditions must be identified early in

order to help assure that they and their families receive the care and assistance to prevent future morbidity and promote optimal development. Advances in brain research, the Human Genome Project, and increased effectiveness of early intervention have expanded our capacity to identify children with special health care needs and offer an opportunity for early intervention. Fiscal year 2003 funding at \$10 million includes grants to all States that apply to achieve universal newborn hearing screening and assure linkage to medical home, early intervention and family-to-family support.

6. Assure successful transitions to all aspects of adulthood, including adult health care, work and independence. Children with special health care needs, including children with ASD, as they become adults, must be able to expect good health care, employment with benefits, and independence. Health care services must not only be delivered in a family-centered manner, but must prepare individuals to take charge of their own health care and to lead a productive life as they choose. Current discretionary grant funding includes grants to States for implementation, a national resource center and technical assistance to address special issues such as availability and access to adult health care. \$1.8 million was funded for this effort in 2003.

All State title V programs that receive funding from HRSA must report annually on their activities that address these 6 components to achieve appropriate community-based service systems for children with special health care needs. Other HRSA activities that provide support for children with ASD include:

- In response to the Children's Health Act of 2000, the Interagency Autism Coordinating Committee (IACC) was formed. HRSA serves on the IACC and meets on a semi-annual basis to enhance coordination and effectiveness of autism research and service activities across the federal government and with public stakeholders. One of the main goals of this committee is to promote the integration of autism services throughout the lifespan. Current challenges that are addressed include the issues raised for those living with autism who must confront fragmentation of services, especially at the interface between those services provided through the health, education and social service systems.
- As part of the National Training Curriculum on medical homes, The National Center for Medical Home Initiatives has recently completed a specific module to provide early, developmental and behavioral screening. This Center receives approximately \$700,000 annually to support universal implementation of the medical home concept for children with special health care needs.
- In fiscal year 2003, HRSA awarded a \$1 million grant to the Geisinger Health System in Danville, Pennsylvania to develop a medical home model of care and a related set of tools that will be used to improve early detection, access to diagnostic and evaluation services, and continuity and appropriateness for care for individuals with ASD and their families. Educational tools from this grant will be disseminated to State programs and communities to strengthen and expand integrated community services for children with autism.
- HRSA recently held (October 27-28, 2003) an expert workgroup meeting for families of children with autism. The primary goal of the workgroup was to

provide us with information on service needs from the families' perspective and to discuss with families potential strategies to address the identified needs. The information obtained from the workgroup meeting will be shared with the IACC.

- HRSA has two long-standing programs that are relevant to the training of health professionals to serve persons with autism and other developmental disabilities. The Leadership Education in Neurodevelopmental Disabilities (LEND) program funds 35 LEND programs across the United States to train individuals from a wide variety of professional disciplines to assume leadership roles and to ensure high levels of clinical competence to improve the health of children who have, or are at risk of developing, neurodevelopmental or other related disabilities such as autism and mental retardation. Interdisciplinary faculty and trainees include audiologists, dentists, health administrators, nurses, nutritionists, occupational therapists, physical therapists, physicians, psychologists, social workers, special education professionals, and speech language pathologists. These programs are currently funded at \$18 million.
- HRSA funds nine programs at institutions of higher learning to enhance the behavioral, psychosocial and developmental aspects of general pediatric care. These programs support fellows in behavioral pediatrics to help in their development for leadership roles as teachers, researchers, and clinicians. Over the long term, we believe this will aid in the identification and treatment of children with ASD. This program is currently funded at \$1.3 million.
- HRSA currently funds a study addressing autism entitled, *Early Detection of Autism: Comparison of Three Screening Instruments*. This University of

Connecticut 5-year study involves the comparison of three parent checklist screening instruments for 24-month olds; (1) the Checklist for Autism in Toddlers (CHAT) – parent report section; (2) The Modified Checklist for Autism in Toddlers (M-CHAT); and (3) The Yale Autism/PDD Screener. A projected 120 children will be evaluated at 24 months and again at 42 months. We are confident that this study will provide useful information for support services for children with ASD.

- HRSA funds Health Centers in all States. Once a child, as a primary care patient, presents suspected symptoms of ASD, primary care clinicians seek a specialty referral, generally outside the purview of the health center. The primary care clinician may tap any available resource such as a community mental health center or other federally funded program. The clinic would also be expected to make referrals to and coordinate with individuals responsible for providing services under programs authorized by the Individuals with Disabilities Education Act, including the Grants for Infants and Families program. However, primary care clinicians maintain oversight of the patient with the diagnosis. Although treatment for autism is not under the purview of the health center, the health center will continue to address the primary care needs of the child such as immunizations, screenings and treatment for acute conditions. Also, as a medical home, while the health center may not treat autism, it is responsible for the linkages and ongoing follow-up.

This is a summary of HRSA's activities to provide assistance to persons with autism. These activities adhere to applicable law protecting personal and medical data.

We call upon our partners to join us in a common effort to develop and improve community-based systems of care for all children with special health care needs and their families. It will take the joint efforts of all partners to make a difference for these children and their families. Thank you for the opportunity to appear before the Committee.

Mr. BURTON. Thank you, Dr. van Dyck. The two areas I was talking about before I had a brain lapse was the IDEA program, so that we get adequate funding to help these children with special education needs, and the second was a Vaccine Injury Compensation Fund, which needs to be revised.

That is going to be done legislatively, but it would help a great deal if we can get our health agencies to get behind that effort. One of the problems that we have with the Vaccine Injury Compensation Fund is it was supposed to be nonadversarial, and I know you can't do anything about this but I would like for you to carry this back to our health care agencies, because Henry Waxman, who was my ranking Democrat on my committee when I was chairman, he and I sponsored a bill that would have made it easier for parents to have access to that fund who have had damaged children.

And while it is nice that we have your agencies working together to help assist these families, the cost is huge. We have had people lose their homes, mortgage everything they have, the mental anguish that they go through trying to take care of their kids and worry about them for the future, because we are going to grow old and die, and these kids are going to live to a normal age in most cases. And they are worried about what is going to happen to them if they haven't had proper training.

So we need to make sure that the parents of these children and the kids themselves have access to the Vaccine Injury Compensation Fund. It has over \$3 billion in it now, and they are paying virtually no claims. We have said to the pharmaceutical industry that is very concerned about class action liability suits that we would consider holding them harmless if they would put more money into the fund to make sure these parents and these children were taken care of, and if the fund started to be depleted there could be an excess charge for each shot added to the shot, to make sure that those people are taken care of, because children who are damaged, we believe many of them have been damaged by things such as the mercury in vaccines, that they should be compensated and taken care of.

So I hope you will take that back. Ask them to, the leaders of the health agency over there, to assist Henry Waxman and myself to get that legislation passed so that we can help these families who are really suffering right now.

Dr. VAN DYCK. I will relay that.

Mr. BURTON. Thank you very much. And also the IDEA program, we need to get more money into that. I will do my part here at the Capitol.

Now, you said that the Health Resources and Services Administration ensures access to comprehensive health care through the Medical Home Program. Can you tell me what parents should do, what they should do to try to have access to that, and what the—because a lot of those people, they look at the bureaucracy and say, what the heck do I have to do to get these kind of benefits? They don't know. So can you give us a rundown on what the benefits are and what can be done to make sure that people have access to them.

And, also, just throw in one more thing, if you are getting adequate funds to fund these programs.

Dr. VAN DYCK. The Title V block grant program provides funds to all States by a formula. The Title V Children with Special Care Needs program, through the Title V block grant, provides funds to every State health department to, among other things, provide care for children with special health care needs.

Mr. BURTON. So they would apply through the State health department?

Dr. VAN DYCK. So a family would either call their local health department, their local public health nurse, the State health department, the State maternal and child agency, and that agency would put them in touch immediately with the appropriate program.

Many States contract with locals, local health departments as well. Many States have clinics in local health departments for these children, early identification types of clinics. So that would be the best place for families to call.

We help financially those who are poorest, but we often coordinate the care through the medical home concept, where we try to provide referral, comprehensive care, competent care, culturally competent care, coordinated care for families. Even though we may not be able to help them pay for this specific health care, we may be able to help them find their way through the morass of services that are so necessary.

Mr. BURTON. How much money is appropriated to block grants to the States for this?

Dr. VAN DYCK. The block grant to States program is at \$730 million. States must match the money 3 State dollars for every 4 Federal, and most States actually provide more than that. Of the money going to States almost—when it is combined with the State dollars, almost half of it is for children with special health care needs. They feel that is such an important area.

Mr. BURTON. Do you have this information posted on your Internet Web sites?

Dr. VAN DYCK. Yes, we do.

Mr. BURTON. I wish that we could get it out to these various parent groups that have autistic children and children with special needs, because a lot of people have contacted us, and they don't know where to turn.

Now, in Indiana we went to the State legislature, and we were able to, on a limited basis, we would like for it to be broader, but on a limited basis get the Medicaid program to take care of children with autism, because before that it wasn't considered a health issue, it was considered a mental issue, and it wasn't covered under Medicaid. We have gotten that changed in Indiana to a degree.

But I think additional funding is probably going to be needed, and I don't know that the States can handle all of that themselves. So one of things we might take a look at is through our health agencies here in Washington increasing the appropriation for block grants so there can be more money.

Dr. VAN DYCK. You mentioned IDEA earlier, getting children into the early intervention system through the education process. Kids zero through 3 in many States are served through our State Title V or MCH block grant. But it is a partnership, education providing

many of the educational services or educational-related services, but not often a whole range of health-related services.

And so it really requires a partnership between IDEA agencies at the State level and the maternal or child health or State health agency at the local or State level to really develop a full-fledged program for these children.

Mr. BURTON. I understand that. The problem in both areas are resources. And since I have been involved in this personally, my daughter at her school, my grandson was having trouble with speech and some other problems. And so the doctor that reviewed my grandson's case said, well, he needs 3 days a week of speech therapy.

Well, we said 2 days would be enough. They said they would give him half a day, which was totally inadequate and he would fall further and further and further behind. So more money needs to be used for that. And the States are pretty strapped right now like the Federal Government. We need to take a hard look at how we are allocating resources now.

HHS gets billions and billions of dollars. I don't know how much. Does anybody know how much they get a year? But it is a lot. I just wish whoever is in the appropriating process over there at that agency, after you get the appropriation from Congress, would take a hard look at the developmental disorders, including autism, that these kids are having to go through and see if we can't increase that block money that is going to the States to help with that.

And then the IDEA program we will have to take care of here through direct appropriations. Let's see what else I have here.

Now, the Federal Government grants funds to the State health agencies to disburse Medicaid waivers and autism waivers. Is your agency charged with managing those funds?

Dr. VAN DYCK. No, sir.

Mr. BURTON. You are not. Well, you say on your Web site that—for these grants and these benefits that your Web site will—you tell them where to go.

Dr. VAN DYCK. The HRSA Web site, which is www.hrsa.gov, can point to the MCH, Maternal and Child Health Bureau Web site, or www.mchb.hrsa.gov will get the Maternal and Child Health Web site. For example, I can look up that Web site and see that Indiana receives about \$12 million for the block grant, puts in another \$13 million of State money, for a total of about \$25 million for maternal and child health services, spending about half of that on children with special health care needs. And there will be the person to call in Indiana who would help know about the program, where parents could call and sign up. So that person's name would be on the Web site.

Mr. BURTON. But nationwide, how much money do you say that they are block granting out?

Dr. VAN DYCK. Nationwide, the maternal and child health block grant is \$730 million. About \$600 million of that goes to the States, divided among them.

Mr. BURTON. So the States, they have to match that with about what, \$700 or \$800 million?

Dr. VAN DYCK. They have to match 3 State for every 4 Federal. So for \$600 million they would have to match about \$450 million.

Mr. BURTON. So we would be up about a billion.

Dr. VAN DYCK. But they overmatch that. This total program represents about \$4 billion of services when the State money is added in.

Mr. BURTON. That is—with all of the problems there are, that is still——

Dr. VAN DYCK. That is quite wonderful.

Mr. BURTON. Is it adequate to handle the needs?

Dr. VAN DYCK. I would hate to sit before you with increasing needs and State budgets declining that we don't feel an increased pressure of services, for service provision, from our Federal dollars.

Mr. BURTON. Could you do me a favor and provide for the subcommittee any information that your agency has on their cost projections? Because although that is taken out of HHS money, you know, if we know here in the Congress what the projected need is going to be we can talk to the HHS leaders as well as the members of the Appropriations Committee here in Congress to see if we can't make sure there is not a shortfall.

Because these parents, especially parents of autistic kids are really taking it in the head when they talk about medical expenses, expenses that—all kinds of expenses that they have to incur to deal with these kids.

People who haven't received the grants, how do you help them have access and get those grants?

Dr. VAN DYCK. HRSA publishes each year a document called the Preview. It is already published. It is on HRSA's Web site, and it lists every grant competition coming up for this fiscal year.

Mr. BURTON. What I would like to do, can we tap into their Web site and put it into our Web site so people who want to contact—I would like to do that. I would like to cross-pollinate our Web sites so that people who are—they know that I am very interested in the autism issue, so that they can get ahold of my Web site and access this information. Did we get that Web site address again?

Dr. VAN DYCK. www.hrsa.gov. HRSA is one of the few agencies that publishes for the entire year the full complement of grant competitions for that year.

Mr. BURTON. So OK. So we can get that on there and interested parties can find it, not only from your Web site but from ours as well.

Mr. BURTON. Dr. van Dyck, I appreciate you very much coming. I hope when you go back to the health agencies you will tell the people over at HHS I am not the SOB that everybody thinks that I am all of the time, just once in a while.

Dr. VAN DYCK. I would never say that, sir.

Mr. BURTON. I know you wouldn't say that, but I know that a lot of those people over there are very concerned. In fact, some people told me that they don't like to come before our committee because we are very difficult to deal with. All I can say is that if we are, it is only because there is a great deal of concern about these kids. And when you talk to parents, and my grandchild is doing better. But when you talk to parents who have kids who are 14 years old, who attack them, and they have to lock the door between the child and them, so that they don't get hurt, and the house is being destroyed, they are running out of money, they don't have

money for expenses let alone taking care of the child and food on the table, and they wonder what in the hell is going to happen to my child in the next 4 or 5 years, it is really tragic.

And it is not that our health agencies don't have a heart, I think that they do. But I think that there needs to be a realization that we have to look very hard at what the needs are and provide for those. And I think we have been falling short a little bit there. And that is why I would like to work with you at the health agencies to find out what needs to be done, and what we need to do in Congress to get it done.

And if the health agencies need to reevaluate how much money they are putting into, say, you know, developmental disorders in general, autism in particular, maybe we can talk to them and work with them to get more money put into that so parents can deal with that better.

Dr. VAN DYCK. Thank you very much. We look forward to working with you. I should say that the families and children with special health care needs in the country are lucky to have such a committed person advocating for them.

Mr. BURTON. Well, I wish you would call my kids and tell them that, because they don't appreciate me all that much. Thank you very much. I appreciate that very much.

Our next panel is my good friend, Mr. Rick Rollens, co-founder of the MIND Institute at the University of California Davis, and Dr. Steven Edelson, who is the director of the Edelson Center for Environmental and Preventative Medicine, and Ms. Colleen Pettinati. She is the mother of two autistic children.

Would you all come forward and we will get you sworn in and get started on this.

[Witnesses sworn.]

Mr. BURTON. Let's start with you, Ms. Schwartz. And if you could, we are going to have more votes on the floor, if you can try to confine your comments to about 5 minutes, we would appreciate that.

STATEMENTS OF ILENE SCHWARTZ, DIRECTOR, CENTER FOR TRAINING PERSONNEL TO PROVIDE EVIDENCE-BASED EDUCATIONAL SERVICES TO STUDENTS WITH AUTISM SPECTRUM DISORDERS, REPRESENTING U.S. DEPARTMENT OF EDUCATION INITIATIVES; RICK ROLLENS, CO-FOUNDER, MIND INSTITUTE, UNIVERSITY OF CALIFORNIA DAVIS; DR. STEPHEN EDELSON, DIRECTOR, EDELSON CENTER FOR ENVIRONMENTAL AND PREVENTATIVE MEDICINE; AND COLLEEN PETTINATI, MOTHER OF TWO AUTISTIC CHILDREN

Ms. SCHWARTZ. Absolutely. Good afternoon, Mr. Chairman, and thank you for inviting me to come talk to you. I am a professor of education at the University of Washington in Seattle. At the University of Washington I prepare professionals to work with very young children with disabilities, including children with autism. I am also a faculty advisor to the Experimental Education Unit, a comprehensive early childhood program for children with and without disabilities at the University of Washington.

In addition, and the reason I was invited here this afternoon, I am the principal investigator of OSEP-funded projects that are tar-

geted toward developing, evaluating, and disseminating evidence-based strategies for educating children with autism.

I would like to tell you about two of these projects. First, Project DATA is a school-based preschool program for children with autism and their families. Due to our OSEP grant, these services are provided to children and families at no cost to parents.

Initially funded by OSEP in 1997, this program is now supported by local public schools and private donations. Children who participate in our program have all made tremendous gains across all developmental domains. Our first sample of toddlers, children who started our program under the age of 2, are wonderful examples.

After 1 year of intervention, 6 of the 8 children tested in the normal range of development across all domains. At this point, 48 children have completed our program, and 58 percent of these children leave our program and enter inclusive elementary school programs. The families who participate in our program are among our strongest and loudest advocates. Parents are pleased and school districts are pleased.

We have over 100 visitors to the program every year. We have trained early childhood providers, teachers and family members across our State and over 20 other States. Although we are proud of these outcomes, we are concerned when we look at what happens to children when they leave our program and make the transition to elementary school. Although, as I said, 58 percent of our graduates enter inclusive classrooms only 4 years later, only 25 percent of our graduates are still attending elementary school next to their typically developing peers. Most of these children are not successful in general education classrooms, not because of their academic behaviors. Many of these children who are not successful have reading and math skills at or above grade level. Although these children have achieved standards academically, they are suffering behaviorally and socially.

Many of these children do not have friends, rarely make initiations to peers, and often do not respond to the initiations by their peers. Occasionally these children demonstrate behaviors that their teachers consider challenging, but rarely are the appropriate levels of support in place for them.

Although we know quite a bit about what constitutes a high quality effective preschool program for children with autism, we know relatively little about what services should look like for these children as they get older. The challenges of elementary school, middle school and high school and adult life must be addressed by evidence-based instructional programs.

Research is needed to determine what elements must be contained in these programs. Although we know quite a bit about effective programming for children with autism, there is still a huge gap between what is state-of-the-art and what is state of practice; that is, what most children and families face when they enroll their child with autism in their local school district.

To attempt to address this inequity, the Department of Education funded a national training center, which was awarded to the University of Washington. Our center, the Professional Development in Autism Center, has partners across the country at five partner sites. At this point we have been in existence for 10

months and we have already provided training to 47 educational teams from 14 States.

In summary, over 500 teachers, parents, and other interested providers have participated in our activities. To give you an idea of what those activities are like I will tell you in this training we provide to educational teams is individualized, intensive and hands-on. What we know about training educators is somewhat similar to teaching children. We cannot just lecture on best practice and expect people to go home and change their behavior.

Teachers need to see best practice in action, practice implementing these strategies with support, and they need followup support and consultation. For example, this week a team of educators from New Mexico are at the University of Washington for training. From before their visit, an educator from the University of Washington visited them in their classrooms to help begin the training process with a needs assessment.

This week the staff from New Mexico will spend 40 hours with the trainers at the Experimental Education Unit. Part of this time will be lecture, part observing children in a model program, part will be working with children directly with close supervision, and part discussing what they are learning and how they will be able to apply it in their own setting.

Then, sometime in January the staff member from UW will travel to New Mexico again, to help the team with implementation issues and conduct a post-assessment to evaluate the effect of the training. The team members will have access to a problem-solving Web site and phone calls with the training team. All of these services are paid for by the OSEP training center.

You might ask why this level of training and support is necessary. First, as you know, children with autism present a great challenge for public schools. Given their triad of disabilities in communication, social interaction and a restricted or repetitive set of behaviors, children with autism present a diverse profile of abilities that range from children who read well above their grade level to those who are nonverbal.

Next, the environments in many elementary schools and the curriculum used in these settings are not well suited to the needs of children with autism.

Finally, if we are ever going to achieve the dream of leaving no child behind, we need to ensure that all children with autism have access to free, appropriate public education that utilizes evidence-based instructional strategies. These strategies are complex to use and costly to implement. To respond adequately to the autism epidemic, we need to make access to high quality services for those children already identified simple and seamless.

High quality training for educational professionals is an important first step. Thank you.

[The prepared statement of Ms. Schwartz follows:]

Written Statement
Subcommittee on Human Rights and Wellness
House Committee on Government Reform
United States House of Representatives

Written Statement of

Ms. Ilene Schwartz

Director

Center for Training Personnel to Provide
Evidence-Based Educational Services
to Students with Autism Spectrum
Disorders

Representing United States Department
of Education Initiatives

Good Afternoon Chairman Burton and other distinguished Members of the Committee. Thank you for inviting me to come and talk to you today. My name is Ilene Schwartz and I am a professor of Education at the University of Washington in Seattle. At UAW I prepare professionals to work with very young children with disabilities, including children with autism. I also am the faculty advisor of the Experimental Education Unit, a comprehensive early childhood program for children with and without disabilities at the University of Washington. In addition, and the reason I was invited this afternoon, I am the principal investigator of OSEP-funded projects that are targeted towards developing, evaluating, and disseminating evidence-based strategies for educating children with autism.

I would like to tell you about two of these projects. First, Project DATA (Developmentally Appropriate Treatment for Autism) is a school-based preschool program for children with autism and their families. Initially funded by OSEP in 1997, this program is now supported by local public schools and private donations. The children who participated in our program have made tremendous gains across all domains. Our first sample of toddlers, children who started our program under age 2, are a wonderful example. After 1 year of intervention, 6 of the 8 children tested in the normal range across all developmental domains. At this point 48 children have completed our program and 58% of these children leave our program and enter inclusive elementary school programs. The families who participate in the program are among our strongest and loudest advocates. Parents are pleased and school districts are pleased. We have over 100 visitors to the program every year; and have trained early childhood providers, teachers, and family members across our state and over 20 other states. Although we are proud of these outcomes, we are concerned when we look at what happens to children when they leave our program and make the transition to elementary school. Although as I said 58% our graduates enter inclusive classrooms four years later only 25% of our graduates are still attending elementary school next to their typically developing peers in inclusive classrooms. Most often when children are not successful in general education classrooms, it is not because of academic behaviors. Many of the children who are not successful have reading and math skills at or above grade level. Although these children "achieve standard" academically, they are suffering behaviorally and socially. Many of these children do not have friends, rarely make initiations to peers, and often do not respond to the initiations by their peers. Occasionally these children demonstrate behaviors that their teachers consider challenging, but rarely are their appropriate levels of support in place for them.

We need to learn why children with autism are not staying in the educational mainstream. What types of support and explicit instruction do these children require to be successful in these settings. What we do know is that creating effective educational environments for children with autism is complex and costly. Resources, whether they are money, trained personnel, or on-going support for educational teams, limit the ability of local school districts to implement state of the art programs for children with autism and their families.

While we know quite a bit about what constitutes a high quality, effective preschool program for children with autism, we know relatively little about what services should look like for children as they get older. The challenges of elementary school, middle school, high school and adult life must be addressed by evidence-based instructional programs. Research is needed to determine what elements must be contained in these programs.

Although we know quite a bit about effective preschool programming for children with autism, there is a huge gap between what is state of the art and what is state of the practice – that is what most children and families face when they enroll their child with autism in preschool at their local school district. To attempt to address this inequity, the Department of Education funded a national training center, which was awarded to me at the University of Washington, to increase the capacity of local educators to provide high quality, evidence-based instructional programs to all children with autism. Our center, the Professional Development in Autism (PDA) Center, has partners across the country in five partner sites (University of Colorado at Denver, University of Kansas, Oakstone Academy and the Ohio State University, University of South Florida, and Maryland Coalition for Inclusive Education). At this point we have provided training to 47 educational teams, from 14 states. In total over 500 teachers, parents, and other interested providers have participated in our Center's activities in the 10 months we have been in existence.

The training we provide to educational teams is individualized, intensive, and hands-on. What we know about training educators is somewhat similar to teaching children. We cannot just lecture on best practices and expect people to go home and change their behavior. Teachers need to see best practices in action, practice implementing these strategies with support, and need on-going follow-up support and consultation. For example, this week a team of educators from New Mexico are at the University of Washington for training. Before their visit an educator from UW visited them in their classrooms to help them begin the training process with a need assessment. This week, the staff from New Mexico will spend 40 hours with trainers at the Experimental Education Unit at UW. Part of this time will be lecture, part observing children in a model program, part working with children directly with close supervision, and part discussing what they are learning and how they will apply it in their own setting. Sometime in January, the staff member from UW will travel to New Mexico again to help the team with implementation issues and conduct a post-assessment to evaluate the effect of the training. The team members will have access to a problem-solving website and phone calls with the training team. All of these services are paid for by the OSEP training center.

You might ask why this level of teaching and support is necessary? First, as you know children with autism present a great challenge for public schools. Given their triad of disabilities in communication, social interaction, and a restrictive or repetitive set of behaviors; children with autism present a diverse profile of abilities that range from children who read well above their grade level to those who are nonverbal. Next, the environments of many elementary schools and the curriculum used in these settings are

not well suited to the needs of children with autism. Finally, if we are ever going to achieve the dream of leaving no child, we need to insure that all children with autism have access to a free, appropriate public education that utilizes evidence-based instructional strategies. These strategies are complex to use and costly to implement. To respond adequately to the autism epidemic we need to make access to high quality services for those children already identified simple and seamless. High quality training for educational professionals is an important first step.

Respectfully submitted by
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Government Mapping Out a Strategy to Fight Autism

By JANE GROSS

Propelled by the skyrocketing number of diagnoses of the perplexing brain disorder autism in children, federal officials have for the first time mapped out a long-term, interagency plan to deal with the problem.

The plan includes objectives like the development of teaching methods that will allow 90 percent of autistic children to speak; the identification of genetic and nongenetic causes of the condition; and adequate services for all afflicted children in the next 7 to 10 years.

The plan, which is to be unveiled at a major autism conference in Washington that begins today, signals the start of the push-pull process over financing. Such a plan was required by the Congressional appropriations committee that controls the budget for scientific and medical research and education programs of all kinds.

Few of the nearly 150,000 autistic children and young adults now getting special education services under federal law will benefit significantly, experts say, since the most effective treatment involves early, intensive behavior therapy, which is poorly understood and in limited supply.

Autism is a disorder with a wide range of symptoms sometimes so mild as to let a child function in a regular classroom with special services and at other times so severe that a child is mute and institutionalized.

The three-pronged plan sets goals for more coordinated biomedical research, earlier screening and diagnosis, and effective therapy. The plan demands, for the first time, collaboration between scientists, clinicians, educators and policymakers in an array of federal agencies.

"Millions of people need help," said Robert L. Beck, president of the Autism Society of America, the nation's oldest and largest autism advocacy group. "And this is a new opportunity and a very exciting one."

The need is enormous. According to federal education officials, in 1992-93, fewer than 20,000 of the nation's nearly five million special-education students, ages 6 to 21, were considered autistic. Ten years later, nearly 120,000 of six million special-education students had autism. That does not count the 19,000 children 3 to 5 receiving autism services under federal law, or those younger whose numbers have not been tallied.

Nobody knows the cause of the surge, although epidemiologists suspect it is largely a result of refined diagnosis and public awareness. That does not change the dimensions of a problem that strains schools, medical services and families. Nor does it affect forecasts of growing caseloads for decades to come.

Dr. Fred R. Volkmar of the Child Study Center at Yale University, a leading autism researcher and a member of the committee that drafted the 10-year plan, measures the crisis in more anecdotal ways.

Twenty years ago, Dr. Volkmar said, when he told people he worked with autistic children, they often misheard him and thought he had said "artistic." They had never heard of the disorder, which typically affects the ability to communicate, form relationships with others and respond appropriately to the external world.

By contrast, Dr. Volkmar said, it is rare these days not to know someone with an autistic child. He now sees children as young as 12 months, gets referrals from day-care centers and has a two-year waiting list. Were screening techniques to improve so that diagnoses could be made in infants, he would be hard-pressed to find schools, trained behavioral therapists or other services for them.

The plan, which will be reviewed by the Interagency Autism Coordinating Council, established by the Child Health Act of 2000, is presented in broad brush strokes, with few details and no price tags. It was drafted by scientists to assess the state of autism research and identify the roadblocks that might be hindering progress in understanding the cause and the best treatment options.

The plan lays out a timeline, in increments of 1 to 3 years, 4 to 6 years and 7 to 10 years and then ranks goals according to the likelihood of achieving them. Realistic goals in each of the three stages include the development, evaluation and institution of effective treatments, in collaboration with the Department of Education.

More challenging goals, by contrast, include finding effective drugs for the symptoms of autism and identifying environmental factors that may contribute to the development of the disorder.

"The idea is to be challenging everyone in the field to be reaching for the best we can possibly do," said Dr. Steve Foote, the director of neuroscience at the National Institute of Mental Health, which was designated the lead agency by the Child Health Act. The legislation, passed in the Clinton administration, addresses dozens of childhood disabilities.

Some parents are likely to be frustrated by the plan's suggestion that it will take at least seven years to provide treatment for all who need it.

Mr. Beck of the Autism Society of America hoped that long-term research and improved services were not mutually exclusive. "There are good practices out there," he said, "just not enough of them."

He added: "And there's no money on the services and treatment side. What do we do with the kids for the next 7 to 10 years? We have to do both. You cannot just throw away a generation of children."

Many researchers and clinicians in the field credit the advocacy community with galvanizing the government, following in the footsteps of AIDS advocates in the 1980's. There are several such organizations, all included at the conference, that have shifted emphasis from looking for a cure to also fighting for a more systematic study of treatments and more services for children.

There is wide agreement that intensive behavioral therapy, which can include breaking a simple task like hand washing into a dozen component parts, beginning at the earliest possible age, is highly effective for many children. What remains a mystery is which children benefit and why, which techniques work best and whether early improvement is sustained over time, said Dr. Catherine Lord, director of the Autism and Communications Disorder program at the University of Michigan and an

author of the interagency plan.

Parents of autistic children are stymied by how difficult it is to find properly trained behavioral therapists. Like others on the scientific side, Dr. Volkmar said that was because the Department of Education, under President Bush, had been "a real stumbling block." Mr. Beck agreed and said he was "quite excited to see them at the table."

Education officials denied a lack of interest. Robert Pasternack, assistant secretary for special education, said Mr. Bush had been generous in his financing requests for educational services for the disabled. Mr. Pasternack acknowledged a "critical shortage of special education teachers" and said the government was eager to "help states recruit and train them."

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Mr. BURTON. Thank you, Ms. Schwartz. I will have some questions for you on cost and other things in a moment.

Dr. Edelson.

Dr. EDELSON. Good afternoon, ladies and gentlemen of the Committee on Human Rights and Wellness. My name is Stephen Edelson. I want to thank Congressman Dan Burton and Mindi Walker for making this happen. It is quite an honor to be asked to enlighten this esteemed group about my work over the last 9 years dealing with the biology of the autistic spectrum of disorders and its clinical management.

My training in environmental medicine has allowed me to study the molecular basis of disease, including applied immunology and toxicology, clinical biochemistry and free radical medicine. These disciplines are key to understanding and unraveling the biology and the basis for the ASD.

During the last decade, there has been a steady increase in the incidence of these developmentally delayed syndromes called the autistic spectrum.

The numbers have gone from 1 in 10,000 to approximately 1 in 250, and this may be underreported. During the same decade, I began to search for the biological aberration that has led to this occurrence. I developed an interest in 1994, after hearing a thought from someone in the autistic community, "all autistics have food allergies."

Being environmentally trained, my mind wondered about how this epidemic could have begun. And in these cases the brain and the immune system seemed to be involved. And how could that be affected 100 percent of the time?

There it is. Only one reason could relate to this, a toxic injury of some sort. I began the investigation to find common threads of the autistic spectrum in 1994 with the study of 30 children in the Atlanta area. The findings in this group manifested combinations of abnormal processes that were found in 100 percent of the children and many other findings of abnormal function in between 25 and 75 percent of the group.

The three most common characteristics, and found as the roots of the spectrum, were a genetic abnormality and liver detoxification, heavy metal burdens with lead, tin, nickel and mercury, and toxic chemical burdens with pesticides and petrochemicals.

In addition, the following were also pieces of the puzzle; 70 percent of the children maldigested; 30 to 40 percent had malabsorption syndrome; 50 percent of the children had an autoimmune encephalopathy, their immune systems were attacking their brains; 100 percent had food allergies and activated immune systems; 75 percent had damaged intestinal linkages called a leaky gut; 100 percent of the children had significant nutritional deficiencies, and approximately 65 percent had massive free radical stress, which is oxidative injury.

Although this studying of these children was done without aged-matched controls, the numbers of children, approximately 150, and the laboratory's reference ranges allow us to speculate that these are the roots of the autistic spectrum. And we leave it to the researchers at the universities to do more detailed scientific work to prove the hypothesis.

I am a clinician, not a researcher. I take care of autistic children and get them well. It is of great importance to mention that not only do we have the large numbers and the reference ranges, but we have shown over the years that by reversing the abnormal biology of these children, they improve dramatically, between 60 and 100 percent, depending on the age when the treatment is begun, the aggressiveness of the therapy and the commitment of the parents to doing the work necessary.

The therapies that I am talking about include heavy metal detoxification using chelation, chemical detoxification using sonar depuration therapy, nutritional therapies, dietary therapies, and at times gamma globulin therapies.

Over the last 9 years, we have published several studies in peer review journals, lectured about the subject in several organizations, and in April 2003 released my book, *Conquering Autism*, to the public. The message of my 9-year journey in developing theories and innovative therapies for this illness are all contained in these pages.

I am hoping that the message I have offered to the public and now to our government will open the eyes to the real culprit in this illness, the poisoning of the world, and so affecting first the most vulnerable of humans, the fetus and the newborn. We all know that this illness is costing our economy billions, and ruining the lives of families and preventing the maturing of a segment of our population.

There is a light at the end of the tunnel, and I have made it possible for parents to attain great changes in the lives of their autistic children. We need this type of innovative work to be available to the masses that currently either don't know it exists or cannot afford to do the work needed to help their children get well.

We ask of this fine body of lawmakers to allow this nontraditional science to be available to all that would like to use it. It is up to all of us to do everything possible to improve the functional life of all of our children.

Mr. BURTON. Thank you.

Ms. Pettinati.

Ms. PETTINATI. Good afternoon, ladies and gentleman of the committee. My name is Colleen Pettinati. I would first like to say what an honor and privilege it is to be here.

I have two beautiful children, Michaela, age 9, and Jonathan, 7 years old. Both of them have been diagnosed with pervasive developmental disorder, also known as autism.

At 2 months old, Michaela experienced collapse shocked after receiving six immunization shots in the same day. It was a frightening experience, one I really didn't understand at the time. When I brought her back to the pediatrician, he assured me that she was fine. At least she appeared that way when he saw her. From that point on, she never seemed to hit her milestones. Her doctor was not really concerned.

By the time Michaela was 2 years old, I realized she was not well. She had severe behavioral problems, night terrors, extreme anxiety, echolalia and no sense of danger. She was also suffering physically with chronic ear infections, continual explosive diarrhea

and febrile seizures. In my opinion, this is a little extreme for the terrible twos.

I then began my journey through the band-aid approach of mainstream medicine. After receiving the long-overdue diagnosis of autism, it was recommended that Michaela should be put on Prozac, and when my son was diagnosed at 23 months, it was recommended that he should be on Ritalin.

Instinctively, I knew this was not the answer, so I dug my heels in and started my search for answers. I attended conferences and read books on the biomedical approach to autism. This made sense to me.

Finally, my research led me to Dr. Edelson of Atlanta, GA. By this time Michaela was 6 and Jonathan was 4. He addressed all the areas which I knew in my heart were influencing my children's poor health and delayed development. Of course, none of tests or treatments were covered by insurance because they are not used by mainstream medicine.

It took my husband and I 2 years to figure out a way to get the money to treat our children. This was the most difficult 2 years of our lives, knowing that there were treatments out there that could help make our children healthier and we could not afford them.

We had no choice but to ultimately sell our home in Massachusetts, leave our family and friends behind and everything familiar to our children and move to Atlanta. We knew we had to use the equity from the sale of our home to try to save our children from this devastating disorder.

The tests revealed exactly what I had suspected and then some. My children were suffering from heavy metal toxicity, immune dysfunction, abnormal liver detoxification, malabsorption, leaky gut, nutritional deficiencies, multiple food allergies and chemical sensitivities. Worst of all, they have antibodies against their brains.

After 4 months—I am happy to say that after 4 intensive months of therapy at the Edelson Center, my son has improved dramatically. His expressive and receptive language has blossomed. His eye contact has improved. His physical health is much better as well. Jonathan is socially interacting with his peers and keeping up academically. He is in a typical first grader, with the help of an aide.

My daughter Michaela's improvements have been more subtle. She requires more treatment.

Our insurance company has paid very little, approximately \$3,000 to date. We still cannot afford all the treatments necessary to save our children.

To date, my husband and I have spent \$50,000 in cash and have taken out a \$30,000 home equity loan that is dwindling away. We both work full time and have no family nearby to help us take care of our children. We bet everything we had on a nontraditional treatment because there was no hope for our autistic children in the world of mainstream medicine.

I strongly believe that Dr. Edelson's treatment protocol should become mainstream so every autistic child has a fair chance of recovery and the financial burden should not be put on the parents.

In conclusion, the toll of autism socially, mentally, emotionally, physically and financially is enormous. The lack of knowledge sur-

rounding this disorder increases our burden to an almost intolerable level, but we know we must go on and save our children.

Mr. BURTON. Your situation with the six shots in 1 day with your daughter sounds a great deal like my grandson. He received nine shots, seven of which did contain mercury, and it was dramatic. How quickly after she received those shots did you notice a change?

Ms. PETTINATI. It was like 4 hours later.

Mr. BURTON. It was very close.

Ms. PETTINATI. She went into collapse shock. When I brought her back to the pediatrician, he said, oh, she is fine. There is nothing wrong with her. I didn't put two and two together until probably 4 years ago. I read a book that explains exactly what she went through. It was collapse shock.

Mr. BURTON. Did you get a chance to check to see what was in those vaccines? Was it thimerosal in there?

Ms. PETTINATI. Absolutely.

Mr. BURTON. Do you know how many of the six shots contained thimerosal?

Ms. PETTINATI. You know, I really can't tell you offhand.

Mr. BURTON. You probably couldn't find that if you went back.

Ms. PETTINATI. DPT, they have hepatitis B. I know those—at least those three do contain it, and that is what she received that day.

Mr. BURTON. Have you applied to the Vaccine Injury Compensation Fund?

Ms. PETTINATI. I haven't applied to the fund.

Mr. BURTON. You probably have missed the window. We are trying to get that changed so there will be a look-back provision. The problem is not in the House. It is in the Senate. We are trying to get them to go along with the legislation that Congressman Waxman and I sponsored which would give you people about 18 months to 2 years to file and would have about a 6-year look-back provision in it so people who have had damaged children can get into the program and at least make the application. So we are going to work on that.

You said you're training, Ms. Schwartz, you are training educators from around the country. How is that funded?

Ms. SCHWARTZ. It is funded through the OCEF training grant.

Mr. BURTON. Is there adequate funds there for that training?

Ms. SCHWARTZ. Well, we could always do more training. I think that, clearly, we have very generous grant, \$1 million a year for 5 years.

Mr. BURTON. That is coming from?

Ms. SCHWARTZ. OCEF. But there are a lot of school districts in this country, and one of the problems that we have is that we are really—it is really a drop in the bucket to the amount of training and technical assistance that needs to be provided.

One of the issues about providing intervention to children with autism—and they talked about this at the autism summit yesterday and today and we all know this—is the children are so diverse in that their behavioral profiles are so different. So teachers need some ongoing support and consultation on how to help particular individual children. That kind of supervision and training is costly.

Mr. BURTON. You get into how the teachers can deal with the behavioral problems as well?

Ms. SCHWARTZ. Absolutely. That is an important part of our training. In addition to making sure that they have evidence-based strategies to teach new skills, at the same time they need to use positive behavior support strategies to make sure that appropriate behavior is being reinforced and not inappropriate behavior.

Mr. BURTON. There have been cases where children who were autistic who were making progress as far as their education have been expelled from school because the teachers can't cope with them. I am sympathetic to the teachers. It is hard to deal in this day and age with children who don't have any disabilities, let alone children who are suffering from things like autism.

So what we are going to try to do is find out how much funding your training program needs that you are not receiving. I wish you would give us that information and then find out through the IDEA program how much more money we can get for that from the Federal level so that the States will have more money to deal with it. But I am still concerned about how you are going to deal with those behavioral problems.

My grandson is doing a lot better, and I am looking at it from him because I have seen this firsthand. He is doing better. But there was a time when he was flapping his arms, running around, banging his head and hollering at inopportune times. It is hard for a teacher to cope with that.

How do other teachers deal with it? How do you tell teachers to deal with that sort of thing?

Ms. SCHWARTZ. Well, first of all, thank you for your support, but there is a strategy, a way of dealing with challenge behavior that we call positive behavior support. One of the things we know about challenging behavior now, whether it is flapping your hands or hitting someone else, is that those behaviors serve a function, and we need to know what the function is.

For some children the function is saying, hey, I need attention. For other children, it is escape, saying this is too hard or I don't want to do any more of this. For some children, it's sensory. For example, the lights in here bother me, or it is too loud.

One of the things we need to do is identify what that function is, because we can then help the child achieve that function in a more appropriate way.

Mr. BURTON. How in the world do you teach a teacher all those things so they know how to recognize it?

Ms. SCHWARTZ. That is one of the things we very much are struggling with, is the idea that school districts really need to have someone on staff, given the incidence of autism now, who is more trained than the average teacher. Because the reality is we are never going to get the average teacher up to that level of training. But there are strategies that can be implemented in the classroom that are not that difficult if you have frequent, ongoing support from a mentor or a coach to implement those strategies.

Mr. BURTON. What I would like for you to do, if you could give us in writing your recommendations, maybe we could submit those.

We have the gentleman from our health agency who is here, Dr. van Dyck. If we could get those recommendations, maybe through

Dr. van Dyck or other people at the health agencies, we could pass those on and add that to the mix as far as maybe getting additional funding to deal with this problem.

There are so many school districts and so many kids who are suffering from these development difficulties orders, autism and others, that we really need to have more education on how to cope with them.

Ms. SCHWARTZ. Absolutely.

Mr. BURTON. If you can get that information to us, we will get it to Dr. van Dyck and have it passed on to some of others over there.

Ms. SCHWARTZ. Absolutely.

Mr. BURTON. Are you familiar with that at all, Dr. van Dyck?

Dr. VAN DYCK. Yes.

Mr. BURTON. Are health agencies already working on that to a degree, how to teach teachers to deal with and cope with these kids?

Dr. VAN DYCK. Well, I think we leave the teaching of the teachers to the education agency, but, again, it is this partnership between—it is an important partnership between teachers and the health professionals, because they help interpret this.

Mr. BURTON. If we can get this information, we will pass it on to Dr. van Dyck and others over there and it will be included in part of the mix.

Dr. Edelson, you said you review the abnormal biology; and after you do that, you use procedures that are not recognized by the conventional or regular medical profession. You use such things as chelation. How do you check out the normal biology or the abnormal biology of the child?

Dr. EDELSON. First, let's talk about heavy metals like mercury, lead, nickel, etc. We use what we call a challenge, where we put chelators into the child, depending on the weight of the child.

Mr. BURTON. You do that through the bloodstream?

Dr. EDELSON. Yes, we do that IV. We give an IV. Then we measure the urine output over 12 to 24 hours.

Mr. BURTON. Checking for mercury, as well as other heavy metals?

Dr. EDELSON. Oh, yes, we check out all the heavy metals. We send that to a reputable laboratory that does the work, measuring micrograms per liter of metal that comes out.

Usually, before we even do the challenge, we do a 24-hour urine without any challenge to see if anything is coming out or anything is present without the actual chelator, so you can compare what it is like before and after a challenge. And you see a big spike—if the heavy metals are coming out, you see a big spike after the challenge is given. That way you determine the total burden of heavy metals in the child, and then you set up a program that the child gets weekly treatments of chelators to remove these metals from their body.

Mr. BURTON. Well, I think you all were at the conference yesterday, were you not?

Dr. EDELSON. No.

Mr. BURTON. You were not there. Well, at the conference yesterday I showed a tape of a study that was done at the University of

Calgary in Canada that showed what happened to brain cells when a very small amount of mercury was put in close proximity to them. Of course, it did destroy them.

If you find out a child has had, say, from mercury, which they think is one of the major culprits in their body, and they are suffering from autism, you can chelate that out of their body. In your experience, what about regeneration of the brain tissues? I have been told that once that damage is done, you can't do much about it.

Dr. EDELSON. That is not true, at an early age. Absolutely not. We know that, at least up to 10 or 11, that you can completely turn around what has happened to brain cells. A classic example is you can take a 6-year-old, remove half their brain, within 2 years that child will be perfectly normal. If you try it on a 15-year-old, you have a totally disabled individual. The brain cells regenerate. They take time to do it, but it completely heals.

If Mindi will show that videotape of a child, just a 2-minute videotape of a child, you will see a child before we removed the mercury from the body of the child and after. We will see the behavior of this child.

Mr. BURTON. We will do that in just a second.

I would like to ask a question about that. Have you kept records of all this that you can pass on to our health agencies? You know, when I talk to our health agencies, there is a built-in reluctance to believe that chelation, for instance, and things like you are talking about really do any good. They always want to do a double-blind study, and that takes 5 or 10 years. By the time you get through it, a whole generation of kids have been left behind.

Dr. EDELSON. That is the classic. What can I tell you?

Mr. BURTON. First of all, how do you get around some of our health agencies and maybe some of the condemnation that doctors receive for doing these procedures?

Dr. EDELSON. They can condemn me all they like. I am getting children well, and I am willing to put up with their condemnation.

Mr. BURTON. And you kept records showing the improvement of these children?

Dr. EDELSON. I have records on all of this.

Mr. BURTON. How many children have you helped?

Dr. EDELSON. Oh, gosh, 100.

Mr. BURTON. One hundred. Would you mind sending us any kind of a medical record history?

Dr. EDELSON. I can't do that, according to HEPA laws.

Mr. BURTON. See, the problem we have—

Dr. EDELSON. I didn't make the laws.

Mr. BURTON. I know you didn't. For me to change those laws is a very cumbersome process, as you might realize. What I am trying to figure out is how we can take the statistical data, if not the personal data of these kids, and give it to our health agencies as some kind of a proof that this stuff works. Because I believe it does work.

Dr. EDELSON. There is no question.

Mr. BURTON. I know chelation has helped in other areas as well with older people as far as their arteries and that sort of thing. So is there any kind of information you could give us without divulging the names and records of these people that would show a child in this age group had this kind of a problem and a child in this

age group after chelation and this sort of thing had this kind of a behavioral improvement and educational improvement?

I know it would be difficult for you to do that. But if you could, if you could send that to us, we could get that to them and at least show them from your research, working with these kids, how that has been beneficial. Maybe we could kick them in the rear end, those who are reluctant to believe this sort of thing, that maybe they should appropriate or spend some of that money we are putting over there to check this out.

Dr. EDELSON. It won't work, but I will do it for you. I know by experience that the lack of knowledge in this group that you are talking about who are going to look at these results, they are going to be putting it down before they are going to accept it. They are going to put it down.

Mr. BURTON. Let me worry about that.

Dr. EDELSON. That is fine.

Mr. BURTON. Dr. van Dyck will tell you the general understanding over there is I am a real bad guy. That is pretty much it, isn't it?

You don't have to answer that. I will tell you I will be very aggressive in asking them—very aggressive in asking them to review your case studies without names or anything so we don't violate any laws or regulations and ask them to take a hard look at it. If they won't, I will call them before the committee and ask them why they won't.

We have all dealt with bureaucracy and sometimes you find a real diamond up there that says, we ought to take a look at it, and then you find some of the hardheads and we have to try to deal with them. Would you get that for us?

Dr. EDELSON. Sure I will.

Mr. BURTON. Ms. Pettinati, you are Italian—I didn't think you are Irish with that name—or your husband is Italian.

Ms. PETTINATI. I am Irish.

Mr. BURTON. But your husband is Italian.

Ms. PETTINATI. Yes.

Mr. BURTON. Tell me how your children have improved since they have gone through this treatment with Dr. Edelson.

Ms. PETTINATI. They are overall much healthier, not so many problems as we previously saw. Socially, they have improved. My son's personality has just—I didn't realize he had such a great personality.

Mr. BURTON. Was this immediate? How long did it take before you started seeing this?

Ms. PETTINATI. For my son, I saw some improvements within a month.

Mr. BURTON. How many treatments did he have in that month?

Ms. PETTINATI. The month, eight.

Mr. BURTON. Were these all chelation treatments?

Ms. PETTINATI. Yes, chelation.

Mr. BURTON. Do you do those a couple a week?

Ms. PETTINATI. Yes.

Mr. BURTON. You saw marked change.

Doctor, when you were chelating, did you note a drop in the amount of toxic chemicals that were coming out of his body?

Dr. EDELSON. We measure the levels after about 3 or 4 months of treatment, because it is an expensive test, so we don't want to do it prematurely. We don't measure it every week.

Mr. BURTON. You started out, and after you do the original urinalysis without any chelating in it, you do the chelation and you can see what it is, and then you test after about 3 or 4 months.

Dr. EDELSON. Three or 4 months. We tested again, and you can see the drop.

Mr. BURTON. But in her particular case, her son started seeing marked change in a month.

Dr. EDELSON. Well, it is more than chelation. She didn't tell you that the child also had about six different therapies in addition to the chelation.

Mr. BURTON. Were those administered by you as well?

Dr. EDELSON. Yes. We are not doing a linear protocol here. It is a multifaceted treatment protocol that deals with all of the abnormal biology, not just the heavy metals. Remember, I mentioned that these children have multiple defects.

Mr. BURTON. Diet and everything else. I see. Well, your son is doing better, and your daughter is not doing that well. How much did you say you spent? \$50,000?

Ms. PETTINATI. So far, \$80,000. But I would do it all over again.

Mr. BURTON. No, no, I understand that. It has put a real financial burden on you and your husband.

Ms. PETTINATI. Absolutely.

Mr. BURTON. Well, you are one of a whole host of parents that have had this kind of a problem. We have been working very hard to get the Vaccine Injury Compensation Fund opened up so a Special Master can look at everybody's case and make a decision that will not be appealed up and up and up like they have been in the past, so parents can get restitution or some compensation out of the funds to help defer—not defer—but help deal with some of these expenses so people don't lose everything.

I don't think we are going to ever find the whole solution to the problem of these kids being damaged. What I am trying to do with this committee is to find out what the cause is. We have looked at the MMR vaccination, and we have looked at the mercury in the vaccinations and so forth. The scientists we have had before the committee from around the world believe that the mercury is one of the major causes, the MMR shot is one of the causes, so what we are trying to do is first identify the problem and then try to find out how to deal with the problem and, if possible, how to cure the problem. It is a very cumbersome problem.

I see you shaking your head there. It is not going to be easy.

Dr. EDELSON. It is because I don't believe the MMR is the cause of autism, and I think there are a number of studies this have shown it isn't.

Mr. BURTON. Look, I am not saying you have to agree with everything we are talking about here. We have had doctors from England who say yes and who say no, and all we think the health agencies ought to do is check it out so we know.

As far as the mercury is concerned, those who have an open mind, there is a universal belief that is a contributing factor.

Dr. EDELSON. Contributing, but I have had 30 percent of the children who do not have mercury, who have other metals and chemicals that are involved in this.

Mr. BURTON. Tell me about that.

Dr. EDELSON. Absolutely lead is a very, very big metal that we find in these kids. Tin is also. These both—

Mr. BURTON. Aluminum?

Dr. EDELSON. They are all neurotoxins. Not too much. Occasionally, we find aluminum present. It is not one of the major ones. But the three major neurotoxins are certainly mercury, lead and tin. We also find a significant amount of nickel, which is an immune disregulator as well, as is lead and mercury. So we have the immune system here being damaged as well as the central nervous system.

Mr. BURTON. That is in your book.

Dr. EDELSON. The entire 9 years of my work, the three studies, all the things about the mercury, it is all detailed in there.

Mr. BURTON. Well, I will try to go through this. But if you could give us—as you might believe, we have a lot of other issues we are working with up here, like the Medicare prescription drug benefit and the war in Iraq and a few other things. What I would like to do is ask you to give us a synopsis, if possible, condense some of these major issues that you think we ought to deal with that we can present to our health agencies so I can go through them more rapidly. I know it asking a lot, because you have a lot on your plate, too. If you could get that for us through Mindi and my chief of staff and the other people, I would really appreciate it.

Dr. EDELSON. OK, sir.

Mr. BURTON. I see Mr. Rollens has arrived. I hope you gave a big speech over there that everybody was listening to.

Mr. ROLLENS. It was presented in the great Dan Burton style, I must say.

Mr. BURTON. I don't know about that. In fact, I am afraid to ask how you define the great Dan Burton style. Never mind.

Why don't you make a statement, if you want to, Mr. Rollens? Then we will get back to questioning. I don't want to hold everybody up too long. Can you confine it to 5 minutes?

Mr. ROLLENS. Thank you, Mr. Burton, staff, members. It is a privilege to be here before you.

Mr. BURTON. I didn't swear you in. I swore everybody in.

[Witness sworn.]

Mr. ROLLENS. Mr. Chairman and members, it is a privilege to be back before you again. I was invited before your committee back in August 1999 and testified before you about the autism epidemic in California and the growing concerns about the role of vaccines in the process of development of autism.

Back in 1999 when I testified under oath, as well, I reported to this committee that California was adding, on average, five new children a day, 7 days a week, with professionally diagnosed, full-syndrome autism.

I wish I had better news to report to you today, Mr. Chairman. But today, in November 2003, a little over 4 years since the last time I reported, it is no longer five new children a day, 7 days a week; it is 11 new children a day, 7 days a week that we are add-

ing to California's developmental services system. These are all professionally diagnosed cases and at a cost to taxpayers of over \$4 million for a lifetime of care for each child that we add to California's developmental services system.

It doesn't take a math wizard to figure out the math, that in our State we are adding \$44 million worth of new children every day to the cost of care for a lifetime of care for children with autism. Just in the first 9 months alone this year, we added enough children with full-syndrome autism to incur over \$1 billion worth of taxpayer liability for the care of that population—California, one State, 9 months, \$1 billion.

The enormity of this problem is beyond comprehension. We are not only seeing a rapid growth in autism, but we are seeing the numbers of these children coming in at a rate that has just literally doubled within the last 4 years.

The numbers I report to you, Mr. Chairman, are documented in a report by the California Department of Developmental Services that is available; and I will make copies available to you and your staff and the other Members showing this rapid increase just in the last 4 years.

The concern, of course, to State government and Federal Government is what are we going to do? How are we going to care for the children that are here today at a cost over a lifetime of care, just in providing shelter, food and programs for those people when they become adults and young adolescents?

The age distribution in our State is astounding. We have—with the other disabilities in California's developmental services system, which includes things like mental retardation, cerebral palsy and epilepsy, you can chart out exactly what the numbers of new cases are in a very predictable way. In fact, the folks in the Department of Finance budget California's over \$2 billion budget for the developmental services system based on this very predictable rate of increase.

The autism numbers are just off the chart. Not only are they off the chart, the age distribution in the population is so skewed toward young children it is astonishing. When you look at mental retardation, cerebral palsy and epilepsy, you can see there is roughly the same number of those people with those disabilities at age 25 than those age 10 or 15 years old. But you look at the autism population and you quickly discern that only 15 percent of our autism population are adults over the age of 25 years old. Another 15 percent are between the ages of 15 and 25 years old; and 70 percent, 7 out of 10, are children between the ages of 3 and 14 years old. This is a sobering statistic and a real-life crisis as the tsunami of children reach adolescence and adulthood.

We know one thing about autism for sure, and that is it affects boys at a rate of at least four to one. The thought of thousands of autistic males as young adults coming into our system who need services such as in-home and residential—out-of-home residential placement and care is an overwhelming thought.

We know in our State, for instance, the amount of money we spend on children with autism is, on average, about \$5,000 a year. When those children become adults, it jumps to \$30,000 a year. It is a huge increase. We don't spend—the money in autism services

is not with children, it is with adults. These are in today's dollars with today's demands. Again, with only 15 percent of our population currently adults, what is going to happen when these thousands of new cases of growing numbers of cases of autism reach that level? It is an unbelievable situation.

Back in 1999, your colleague, Diane Watson, who I had the privilege of serving with—I was the Secretary of the Senate for the California Legislature for 24 years, and I refer to her as Senator Watson because she was in the State Senate and the Chair of the Health and Human Services Committee for many years. Senator Watson, now Congresswoman Watson, was the author of the legislation that created the MIND Institute. So this is a special day for me, and I hope—I know how busy she is with votes and all that, but I do plan to stop by and see her. I am privileged to be before your committee for that reason as well.

In 1999, the MIND Institute was created. It was created by four fathers of children with autism. We secured through our efforts over \$80 million of funding from the State of California over those years to create what has become the largest autism research clinic and education program in the country, within 3 years.

We had our grand opening of the building, a 150,000 square foot complex located in Sacramento, and I invite you, Mr. Chairman, and your committee to please come to Sacramento and have a hearing and let us explain and show you firsthand the exciting work we are doing, not only in the traditional autism research but some very progressive areas of research looking at things like the role of mercury, the role of MMR vaccine, the role of other neurotoxic components of vaccines in the development of autism.

Mr. BURTON. Well, let me interrupt you here, because I want to get to questions. We kept everybody here longer than I anticipated today.

Has the MIND Institute come to any conclusions about this tremendous increase in autistic cases out there?

Mr. ROLLENS. Yes, they have. They absolutely believe the increase is real.

Mr. BURTON. I mean, do they have any causation conclusions?

Mr. ROLLENS. Not quite yet, but, as they say in the news business, film at 11. We expect to have some results published within the next few months on some of these very important questions.

Mr. BURTON. You have doctors and scientists that are looking into this out there to come up with some conclusions that they think have some scientific validity?

Mr. ROLLENS. Absolutely. The MIND Institute is all about good science research not only in clinical research but in biomedical research, and the work that is being done is first class, it is publishable, and it will be published in not only mainstream medical journals but the best mainstream medical journals.

Mr. BURTON. In addition to the research out there, are they doing anything like Dr. Edelson is doing as far as using alternative methods of treatment to help kids?

Mr. ROLLENS. One of the—

Mr. BURTON. Dr. Edelson has used chelation and other treatments which has been beneficial to a lot of children. What do they do at the MIND Institute?

Mr. ROLLENS. One of the dilemmas that we have that we are addressing by doing good science clinical research is finding the efficacy of many of these interventions that we as parents have all tried, and there are many dozens of different interventions out there in the community, some of which have a positive effect. I am a living, breathing example of my son's progress that he has made on many of these types of interventions, including chelation, I can speak as a parent, has been helpful.

But the problem we are having, of course, is unless parents dig deep into their pocket, sometimes into the hundreds of thousands, \$80,000, \$60,000 a shot, to go to folks for these kinds of services—we need insurance companies, we need regional centers, we need school districts, we need all of the folks that are responsible for paying for these interventions to have the science behind the particular intervention in order to get the funding so parents are not on the hook and in many cases literally left destitute by having to pay for these procedures.

Mr. BURTON. What we would like to do—and as long as I am chairman we are going to keep digging into this and trying to get our health agencies to work with these research facilities around the country to come up with some positive responses to it. What we would like to do is—I would like to have your pamphlet there. If there is any additional information you could give to us, we would like to have that as well.

Mr. ROLLENS. In here I do outline and the MIND Institute outlines all the autism vaccine studies so you can see what is in progress.

Mr. BURTON. What we would like to have from Ms. Schwartz is your recommendations on expanding the educational programs for the people in the educational profession so they will know better how to deal with these kids and what we ought to be doing as a government to provide the resources to help those educators to be trained properly.

From you, we need—you know what we need. I know you can't violate, Dr. Edelson, the rules and regulations and laws established to protect patient confidentiality. But, as I said before, if you could give it to us in some kind of form so we can take a hard look at it; and maybe after that we can get some of our health agencies to sit down with you and maybe take a closer look at case studies within the confines of the law.

All I can say to you is I am very sympathetic, Ms. Pettinati, because we have gone through it, and sitting in the audience I think are a lot of parents and people who have spent all that money and toward that end we are going to continue to try to do something about the Vaccine Injury Compensation Program. We continue to need everybody's help putting pressure on Congressmen and Senators to push for some changes in that program so we can get some money to the parents so they don't go bankrupt and then they can use that money to help get their kids better by going to facilities like Dr. Edelson's and others.

Ms. Watson has requested that her statement be submitted for the record. She could not make it. We will do that. I will tell her, Mr. Rollens, that you still love her dearly and you missed her today.

With that, unless there are any other questions I might ask, if you could get us that information, we would really appreciate it. We will not just let it lay around here. We will use it, I promise you.

Mr. ROLLENS. Please come to California.

Mr. BURTON. I am going to come to California. Representative Watson and I are going to have a hearing on amalgams and mercury in California. We will try to make it in Sacramento if possible so we can go up there and see your facility and try to get a look at that.

If you folks will get us that information, we will take it and run with it. Dr. van Dyck, I hope you will carry back to our health agencies the message that you have heard today; and we need to continue to work with you to find some solutions.

With that, we stand adjourned.

[Whereupon, at 4:08 p.m., the subcommittee was adjourned.]

[The prepared statement of Hon. Diane E. Watson and additional information submitted for the hearing record follow:]

**Government Reform Subcommittee
Human Rights and Wellness
Opening Remarks
November 20, 2003
Congresswoman Diane E. Watson**

Thank You Mr. Chairman. Autism is a brain disorder that affects people's ability to communicate, adjust to different surroundings, and relate to others. A lifelong condition that emerges by the age of three years, autism is three to four times more likely to be diagnosed in boys than girls. Previously, autism was considered a rare disease, affecting roughly 1 in 10,000 children. According to the latest estimates, autism rates in the United States indicate that 1 in every 500 children are afflicted by the

disorder. The rising prevalence of autism is disconcerting, giving rise to the question, “What is being done?”

Mr. Chairman, as an educator in my former professional life, I understand the anguish and confusion that autism spectrum disorders can cause. At the present, the world does not know what causes autism. Given the personal knowledge and expertise already offered by the Chairman on this subject, I would like to focus on my home state of California.

Since the 1980s, California has experienced dramatic increases in the number of children diagnosed with autism. Autism is now more prevalent than childhood cancer, diabetes and

Down's syndrome. If the increase in autism caseload numbers continues, in approximately four years the number of people with autism in the California Developmental Services system will equal each population of people with cerebral palsy and epilepsy in the system.

A report on California's autism population, issued by the California Department of Developmental Services, gives a sobering view of the approaching situation. In July 2003, DDS released a study: *Autistic Spectrum Disorders, Changes in the California Caseload: 1999-2002*. This report states that from December 1998 through December 2002, persons diagnosed with autism served by DDS increased from 10,360 to

20,377. In addition, between 1987 and December 2002, the population of persons with autism served by DDS increased by 634 percent. The Director of DDS asserts that California takes these growing numbers very seriously. Each of the 21,000 persons who have been diagnosed is receiving services through the 21 regional centers and five developmental centers run by the state.

As a State Senator and Chair of the Health and Human Services Committee, I was challenged with the question, “What is being done?” With the proper information, resources, and resolve, we can do many wonderful things. I am pleased to see a representative of the M.I.N.D. Institute, Mr. Rick Rollins, on our second panel

today. In the mid-nineties, I authored legislation to create a center in which research could be initiated on neurodevelopmental disorders.

Families with children who have neurodevelopmental disorders have found few answers to how they can help their children grow into healthy adults. UC Davis M.I.N.D. Institute offers these families new hope in unraveling the mystery that has long surrounded autism and autism spectrum disorders, fragile X syndrome, and other developmental disorders.

The M.I.N.D. Institute brings together diverse groups - parents, educators, physicians and scientists, using an integrated, comprehensive

approach in treating and finding cures for these neurodevelopmental disorders..

The M.I.N.D. Institute is uniquely positioned to take advantage of exceptional expertise at UC Davis. The university offers a toxicological science program, the Center for Environmental Health Sciences, the Center for Children's Environmental Health and Disease Research, the Superfund Basic Research and Training Program, the Center for Neuroscience, the Mouse Biology Program, the California Regional Primate Research Center and the UC Davis Genomics Initiative.

Key research under way at the M.I.N.D. Institute includes:

- **Identifying the similarities and differences among children with autism**
- **Understanding the causes**
- **Working towards prevention**
- **Creating and providing the best treatments**

Mr. Chairman, the M.I.N.D. Institute is a state-of-the-art facility available to address increases in autism, but is it enough? The testimony of each panel today will provide a summary of the National Autism Conference that is convening as we speak. The summit features a public forum to disseminate, evaluate, and

integrate the latest science-based autism information among federal, academic, and community participants. I am very interested in hearing the answer to, “What is being done?”

Thank you, I Yield back my time.



**Written Statement
Subcommittee on Wellness and Human Rights
House Committee on Government Reform
United States House of Representatives**

NIH Autism Research Activities

*The Future Challenges of Autism:
A Survey of the Ongoing Initiatives*

*Written Statement of
Dr. Ann Wagner, Ph.D.
Chief, Autism Interventions Research Program
Division of Services and Interventions Research
National Institute of Mental Health
National Institutes of Health,
U.S. Department of Health and Human Services*



For Release on Delivery
Expected at 2:00 p.m.
On Thursday, November 20, 2003

I am Dr. Ann Wagner, Chief of the Autism Interventions Research Program in the Division of Services and Interventions Research (DSIR) at the National Institute of Mental Health (NIMH), a component of the National Institutes of Health (NIH). I am pleased to submit this written statement for the record on behalf of the NIH. In addition to my role in DSIR, I am actively involved in the coordination, planning, and oversight of autism research activities at NIH, many of which involve inter-Institute collaborations. For example, I am a member of the NIH Autism Coordinating Committee (NIH/ACC). I have been an active participant in the organization and implementation of the NIH centers program called for in the Children's Health Act of 2000 (P.L. 106-310), which we have named the Studies to Advance Autism Research and Treatment (STAART) Centers. I also serve as the Executive Secretary of the Department of Health and Human Services (HHS) Interagency Autism Coordinating Committee (IACC) created under a provision of the Children's Health Act of 2000.

Thank you for an opportunity to discuss NIH research initiatives on autism spectrum disorders. I am a clinical psychologist who came to NIH after a career of providing clinical services for children with autism and their families. As a clinician I have seen firsthand the desire for more definitive empirical answers to clinical questions that can lead us to effective treatments. Over the course of my clinical career I got to know hundreds of families affected by autism spectrum disorders and have a deep appreciation for their urgent need for answers about how best to treat – better yet, to prevent – this serious developmental disorder.

The Children's Health Act of 2000, P.L. 106-310, signed into law on October 17, 2000, authorized the Secretary of HHS to conduct additional activities relevant to autism

and pervasive developmental disorders, including expansion, intensification, and coordination of activities of the NIH with respect to research on autism; developmental disabilities surveillance and research programs; expanded information and education activities; and, establishment of an Interagency Autism Coordinating Committee. The Act also requires that an annual report be prepared and submitted to Congress. The Secretary submitted the first such annual report in mid-2001, and the second annual report in November 2002, and the third report is in preparation. My testimony will emphasize the progress and expansion that has occurred over the past year with regard to research activities.

NIH Research Activities

Within NIH, five institutes are members of the NIH Autism Coordinating Committee (NIH/ACC), an internal body made up of all of the institutes that are conducting autism-related research. Members include NIMH, the National Institute of Child Health and Human Development (NICHD), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), and the National Institute of Environmental Health Sciences (NIEHS). In addition, a staff representative from the National Institute of Allergy and Infectious Diseases (NIAID) participates in meetings. The NIH/ACC functions in a coordinating role for autism research activities funded and conducted by the NIH Institutes.

Over the past six years NIH autism research dollars have risen from approximately \$22 million in 1997 to \$74 million in 2002. Today I will emphasize major activities involving research networks and centers, but it is important to bear in mind that

NIH also funds individual autism research projects in the areas of diagnosis, genetics, neuroimaging, neurobiology, psychopharmacological and behavioral interventions, and services research.

Research Units on Pediatric Psychopharmacology and Psychosocial Interventions (RUPP-PI)

The Research Units on Pediatric Psychopharmacology (RUPP) network was established in 1996/1997 with an initial focus on the multi-site clinical trials of medications that are commonly used in children without adequate data on safety and efficacy. This network has provided a model for designing and implementing multi-site clinical trials with children and adolescents with autism spectrum disorders. In 2002 the network was renewed and expanded to include psychosocial and behavioral interventions as well as pharmacology, and renamed to reflect that change. The Research Units on Psychopharmacological and Psychosocial Interventions (RUPP-PI) sites that are focused on autism spectrum disorders are located at:

- Indiana University
- University of California, Los Angeles
- Kennedy Krieger Institute (Maryland)
- Yale University (Connecticut)
- Ohio State University.

Children's Centers for Environmental Health and Disease Prevention

NIEHS, in partnership with the U.S. Environmental Protection Agency (EPA), has continued its support of autism research through a national network of Centers for Children's Environmental Health and Disease Prevention Research. Two of the Centers, funded in August 2001, focus on possible environmental aspects of autism and related neurodevelopmental disorders. They are located at:

- University of California, Davis

- University of Medicine and Dentistry of New Jersey.

Within the past year, the UC-Davis Center has begun enrollment of autistic children in the first large-scale epidemiologic case-control study of environmental risk factors for autism. This study is collecting extensive information to assess a variety of environmental exposures in the prenatal and postnatal period. The Center at the University of Medicine and Dentistry of New Jersey has begun enrollment and evaluation of children in a unique study designed to provide a comprehensive evaluation of personal, residential and community environments of children with autism to identify any sources of harmful exposures and to develop strategies to minimize risk from such exposures. Several basic science projects conducted at this Center are using cellular and animal models to explore the interaction of model neurotoxicants such as lead and methyl mercury with aspects of early brain development and with the emergence of specific behavior patterns.

The NICHD/NIDCD Network on the Neurobiology and Genetics of Autism

Established in 1997 and renewed in 2002, the NICHD/NIDCD Network on the Neurobiology and Genetics of Autism currently consists of ten Collaborative Programs of Excellence in Autism (CPEAs). Each CPEA has a site-specific, multidisciplinary research program on the causes, brain substrates, functional characteristics, and clinical development of autism spectrum disorders. In addition, each site participates in some trans-Network collaborative studies for which no one individual site has the needed expertise and/or subject population. The CPEA network is now studying the world's largest group of well-diagnosed individuals with autism who have been characterized with regard to genetic and developmental profiles.

NIH has renewed the CPEA sites for an additional 5 years of funding. NICHD

and NIDCD plan to allocate \$60 million in this time period to sustain and enhance the CPEAs. A data-coordinating center (DCC) was established this year to expedite and maximize analysis of the data generated by the CPEA research projects as well as the STAART network. This DCC has started to provide administrative support for all network activities and implements a Web site to foster organization, communication and collaboration. The CPEA sites are located at:

- Boston University (Massachusetts)
- University of Washington
- University of California, Irvine
- University of Pittsburgh (Pennsylvania)
- University of California, Los Angeles
- University of Rochester (New York)
- University of California, Davis
- University of Utah
- University of Texas
- Yale University (Connecticut).

Centers of Excellence

The Children's Health Act of 2000 called for NIH to establish at least five Centers of Excellence in Autism Research. The goal was to establish several research centers that would bring together expertise, infrastructure, and resources focused on major questions about autism. A total of eight centers were funded, two in 2002 and six in 2003, and are named the Studies to Advance Autism Research and Treatment--STAART Centers Program. These centers are located at:

- University of North Carolina, Chapel Hill
- Boston University (Massachusetts)
- Yale University (Connecticut)
- University of Rochester (New York)
- University of Washington
- Kennedy Krieger Institute (Maryland)
- University of California, Los Angeles
- Mt. Sinai Medical School (New York).

The STAART Centers will contribute to the understanding of autism by investigating early detection through behavioral and/or biological markers, efficacy of early interventions, early course of core features, biological basis of the core deficits, efficacy of treatments for social deficits, efficacy trials for pharmacotherapy, genotypic and phenotype of response to treatment, and identification of susceptibility genes. Plans for collaborative projects include multi-site clinical trials within the STAART network, as well as interaction with the CPEA. A single data coordination center supports both CPEA and STAART network functions. These Centers have been awarded with 5-year grants, for approximately \$65 million in total. Coordination and collaboration between the STAART Centers and the CPEA Network is being facilitated in many ways. The single data coordinating center for both networks will facilitate the use of common measures, common databases and data sharing. A joint Steering Committee meeting will occur annually; the first of which is being planned for May 2004 in Washington, D.C. NIH has convened a group of Scientific Advisors, made up of senior scientists and public representatives, who are external both to the NIH and to the funded centers, for oversight and advice on research directions. Cross-network subcommittees and interest groups have been formed and are already active. Investigators at all centers within both networks have adopted these activities with enthusiasm and a strong collaborative spirit.

Genetics and Tissue Resources

NIH has undertaken several activities to increase the quality and availability of genetic and tissue resources to the autism research community. The NIMH Genetics Repository is a national resource that collects, stores, and distributes such materials broadly across the scientific community. Activities for 2003 include an administrative supplements program to promote data sharing in ongoing NIH autism projects. Four NIH Institutes and Centers committed \$2.25

million to support the collection and timely sharing of family data and DNA from their ongoing projects through the NIMH Autism Genetics Initiative (<http://nimhgenetics.org>). Eight applications were funded to provide data and materials on 500 new families through this program. Another administrative supplements program promotes data sharing in ongoing STAART Center projects. Through this program, additional clinical data and DNA on 100 new families, 500 unrelated affected individuals, and 150 autistic individuals enrolled in a new clinical trial will be shared with the scientific community through the NIMH Autism Genetics Initiative.

In addition, NINDS continues to support promising research in the genetics of autism, including core grant support for the development and expansion of genetics resources. This support will enhance the ability of research groups located in the United States, Canada, Europe, and Israel to work collaboratively to discover genes that contribute to autism. These research groups have created a genetic data bank that can be shared across laboratories, greatly increasing the power to discover genes involved in autism.

To take advantage of new molecular methodologies, NIMH, in collaboration with the autism community and other NIH Institutes, is stepping up efforts to establish brain bank collections to study autism. Activities in 2003 included an Autism Brain Banking Workshop in March that was sponsored by the NIH/ACC Institutes. This workshop evaluated current best practices for tissue collection and distribution and proposed effective new mechanisms and infrastructure needed to enhance tissue research in autism. Subsequently, NIMH, NINDS and NIDCD announced a joint effort in supplementing the Harvard Brain Tissue Resource Center (whose principal funding comes from NINDS and NIMH) for the creation and maintenance of a National Autism Brain Bank.

Interagency Autism Coordinating Committee

The Children's Health Act of 2000 authorized the establishment of an interagency autism coordinating committee to coordinate research and other efforts with regard to autism within the HHS. Secretary Tommy Thompson delegated the authority to establish the IACC to the National Institutes of Health (NIH) in April 2001. The NIMH at the NIH has been designated the lead for this activity. The Committee is established and has had five semi-annual meetings and a sixth scheduled for this Friday, November 21, 2003.

Government agencies represented include: NIH/ACC members (NIMH, NICHD, NIDCD, NIEHS, and NINDS), the Health Resource Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC) (specifically, the National Center on Birth Defects and Developmental Disabilities), the Agency for Toxic Substances and Disease Registry (ATSDR), the Substance Abuse and Mental Health Services Administration, the Administration for Children and Families (specifically, the Administration on Developmental Disabilities), the Food and Drug Administration (specifically, the Center for Biologics Evaluation and Research), the Centers for Medicare and Medicaid Services, the Agency for Healthcare Research and Quality, and the Department of Education (ED) (specifically, the Office of Special Education and Rehabilitative Services). A summary of each meeting is posted when available on the NIMH Web site (see <http://www.nimh.nih.gov/events/interagencyautism.cfm>).

The IACC has established subcommittees on autism screening and the organization of autism treatment services. Both subcommittees are now working to coordinate activities among IACC members and with the relevant stakeholders in the medical and services communities.

IACC Science Panel and Matrix Development

The House and Senate conferees considering the FY2003 appropriations for the

Departments of Labor, Health and Human Services and Education, House Report 108-10, requested that the IACC “convene a panel of outstanding scientists to assess the field of autism research, and identify roadblocks that may be hindering progress in understanding its causes and best treatment options.” The final product was to be the development of a research matrix focusing on the causes and best treatment options for autism. In response to this request, the IACC convened a panel of science experts to document both roadblocks to understanding causes and best treatment options for autism, as well as goals and activities to overcome these roadblocks. A list of roadblocks was created, and the autism research matrix was designed to include goals and activities for the next 10 years. The goals and activities generally fall within the following categories: characterization of autism (i.e., phenotype), screening, early intervention, school and community interventions, specific treatments, neuroscience and epidemiology. The science panel suggested items for the matrix last July, and the membership of the IACC will approve the final version of the matrix on November 21.

Autism Summit Conference

In order to expand on the work of the IACC, particularly the work of the subcommittees on early screening and services, a national conference focusing on the federal Government’s role in biomedical research, early screening and diagnosis, and improving access to autism services began yesterday and continues through today at the Washington Convention Center in Washington, DC. This event is entitled “The Autism Summit Conference: Developing a National Agenda.” The goal of the meeting is to provide information to the public on Federal activities relevant to autism and to provide an opportunity to the public to share information with Federal agencies. This is another step in our progress toward a unified national agenda for Federal autism activities. The planning committee for this conference is composed of several Federal and public members of the IACC, and the meeting was officially co-sponsored by HHS

and DOE. Three broad themes will be addressed: a) a public presentation of the autism research matrix; a) screening and diagnosis for review of existing screening instruments and discussion of current clinical practices; and b) autism services throughout the lifespan including discussion of integrating services provided by different systems.

In summary, there has been considerable expansion of Federal programs to support research related to autism spectrum disorders. These activities adhere to applicable law protecting personal and medical data. Communication and coordination among Federal agencies is improved and exciting partnerships between public and private groups are being formed. Enhancing the quality and coordination of autism research activities across the Federal Government remains a high priority.